

TALKING ABOUT AN INVISIBLE ILLNESS: THE
EXPERIENCE OF YOUNG PEOPLE SUFFERING FROM
INFLAMMATORY BOWEL DISEASE (IBD)

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ABSTRACT

Inflammatory Bowel Disease (IBD) is a chronic condition caused by immune dysregulation resulting in chronic inflammation of the gastrointestinal tract. Common symptoms include frequent diarrhoea, abdominal pain, poor appetite, rectal bleeding, vomiting, fatigue, weight loss and growth delay in children. Limited research has explored young people's experiences of talking about their chronic illnesses, particularly illnesses like IBD where the condition for the most part is not visible to others.

This study utilises interpretative phenomenological analysis (IPA) to reflect on the experiences of seven adolescents' disclosure of IBD at school, following the transition from primary to secondary school. Internalised social discourses around the unacceptability of talking about IBD's symptoms, namely diarrhoea, meant that IBD was experienced and managed by the young people as a stigmatised identity. Disclosure was experienced as a risky but potentially rewarding experience, with participants weighing-up potential rewards against anticipated costs. Psychological benefits included: talking to address the need for their post-illness selves to be known by both themselves and others, and to belong. Psychological costs noted included: not talking to maintain their privacy and a sense of control over their lives and illnesses, and to avoid disabling attitudes and responses from peers and teachers. A reciprocal relationship between self-discovery and disclosure of IBD was noted, whereby disclosure seemed to simultaneously be affected and effect acceptance of IBD, with many reporting a tension between acknowledging the reality of their illness and not wanting IBD to be the all defining part of their identity. Disclosure was also described by some as a potentially retriggering the sense of trauma experienced around the time of diagnosis.

The study's findings call for services and professionals in all settings (medical and school settings) to consider disclosure of IBD more holistically as an on-going process, one requiring young people to regularly adapt in the face of new challenges, and to adapt their services and practices accordingly.

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CHAPTER ONE: INTRODUCTION

1.1 Overview

This section provides a review of the literature concerning how people talk about less visible chronic illnesses, focusing on young people's experiences of talking about Inflammatory Bowel Disease (IBD). The literature presented in this chapter was collated in a systematic manner. As will be highlighted in the sections that follow, limited research has explored young people's disclosure of invisible chronic conditions in young people, including IBD. Consequently, literature searches also included the disclosure of other less visible chronic conditions in adults. Papers were chosen for potential inclusion if they offered empirical data on the experiences of people with chronic illnesses disclosing to others (e.g. people disclosing to peers or significant others), as opposed to the disclosing of information to people with chronic illness by others (e.g. professionals disclosing medical conditions to their patients). Owing to the relatively large body of literature certain studies were prioritised over others. As this study is concerned with talking and the experience of disclosing IBD, qualitative studies were prioritised over quantitative studies as studies of this nature tend to provide access to the type of data relevant to this research. Systematic reviews and meta-reviews were also prioritised over articles reporting on single studies. As there are likely to be differences in the experiences of young people based on variances in the healthcare and educational systems, as well on prevailing social norms and attitudes, where available particular attention was paid to studies carried out in the UK. Appendix 1 provides a more in depth discussion of the systematic search strategies utilised.

1.2 The impact of chronic illness on young people

Living with a chronic health condition at any age can challenge people's daily functioning, as well as their psychological health (Sirois, 2009). Many studies have shown that young people living with a chronic illnesses are more likely to experience increased psychological difficulties than healthy young people their own age (Cadman et al., 1987; Engstrom, 1992; Lavigne & Faier-Routeman, 1992). Cadman et al. (1987) found young people with chronic health conditions to

be at a greater than threefold risk for mental health difficulties and were at significant risk of experiencing social adjustment difficulties, when compared to young people free of chronic health conditions. In a separate study, when compared to healthier peers, young people with chronic health conditions were found to perform less well academically at school (Taras & Potts-Datema 2005). Whilst this may relate to repeated absences from school, the impact of an illness on a young person's psychosocial well-being may be another contributing factor.

Whilst aging is a biological process, the developmental stage of adolescence is often considered to be a social construct, meaning that there is no universally shared understanding of adolescence and that it may be perceived and hold varied connotations amongst different cultures and social groups. Consequently, the social expectations attached to adolescence, as well as the social interactions young people at this stage of development engage in may vary from one society and culture to another. For instance, in terms of young people living with chronic illnesses, adolescents in Western societies may experience lower levels of expectation in terms of independently managing their illness experiences without on-going parental support, when compared to young people from different cultural backgrounds. While the stage of adolescence may be socially constructed, it is typically said to mark a transitional phase of psychosocial development between childhood and adulthood (Bailey, 2006), where the cultural focus tends to be on the preparation of children for adult roles. Adolescence is typically construed as being a challenging stage in life, even in the absence of chronic illness, owing to the significant and multiple changes experienced in psychological, social, and physical domains (Williams et al., 2002; Karwowski et al., 2009). Within most psychosocial theories of development, adolescence is considered to be a time where issues of identity are particularly prominent (e.g. Havinghurst, 1953; Erikson, 1968). The development of identity is, in part, said to be achieved through interactions with others, particularly peers (Erikson, 1968). Research carried out on adults with chronic illnesses acknowledges that the limitations placed upon people with such chronic conditions may contribute to a 'loss of self' (Bury, 1982; Charmaz, 1983; 1994), meaning that the chronic illnesses that people live with may change the way people view themselves. Whilst this concept is yet to be fully explored in young people, it is possible that

adolescents with chronic conditions may experience a similar 'loss of self' and, consequently, may find it challenging to cultivate a sense of personal identity.

In the sections that follow, I will use IBD as an example of a type of chronic illness whose symptomatology poses certain challenges, particularly in relation to disclosure. I will outline IBD's less visible symptomatology in an attempt to explore how this might relate to young people's experience of talking about IBD at school, a place where young people spend a large proportion of their time.

1.3 Inflammatory Bowel Disease

Inflammatory Bowel Disease (IBD) is a chronic condition caused by immune dysregulation result in chronic inflammation of the gastrointestinal tract. Whilst inflammation may develop anywhere along the gastrointestinal tract (from mouth to anus), it is the intestines which tend to become swollen, inflamed and ulcerated. IBD is typically classified into two subtypes, Crohn's disease and ulcerative colitis, which are distinguished according to their anatomical location and the nature of inflammation (Mackner & Crandall, 2007). The typical age of onset is said to be between the ages of 15 to 30, although both sub-types of IBD may occur at any age (Hanauer, 2006). The prevalence of IBD in the UK is estimated to be between 5-20 per 100,000 people (Carter et al., 2004), with 20-30% of cases reported as developing during childhood and adolescence (Griffiths, 2004; Hanauer, 2006).

Both conditions have a relapsing and remitting course. Typical symptoms include frequent diarrhoea (sometimes with blood or mucus), abdominal pain, poor appetite, rectal bleeding, vomiting, fatigue, weight loss and growth delay in children (Mackner & Crandall, 2007). Crohn's and Colitis UK (2011), commonly referred to as the NACC¹, highlight that anal problems, such as fissures (ulcerated cracks), abscesses, skin tags, and fistulae (abnormal tunnels connecting the bowel to other parts of the body) may also be associated with Crohn's disease. Severity of symptoms varies, with some sufferers experiencing mild symptoms while others experience severe and disabling symptoms. As no

¹ NACC is an acronym for the National association for Crohn's and colitis. Whilst it formally adopted a new working name 2010, it is still referred to by this accepted acronym.

cure exists, treatment for IBD attempts to target any inflammation which may cause potential symptoms (Mackner & Crandall, 2007). Consequently, most IBD patients are administered forms of medication aimed at suppressing their immune systems, with the intention of reducing inflammation and its associated symptoms. Nutritional treatments, such as personalised diets and, in some cases, enteral² or parenteral nutrition³; are also prescribed (Mukherjee & Sloper, 2001). Surgery is also used to treat some cases of IBD. Undergoing such surgery may result in a person having a permanent or temporary ileostomy⁴. Relapses of these conditions typically require repeated hospital visits in either an in-patient or out-patient capacity. Although they share some of the same symptoms, IBD is not to be confused with Irritable Bowel Syndrome (IBS). The two conditions are quite different from one another and typically require different treatment.

1.3.1 The impact of IBD on young people

The implications of IBD extend far beyond the health of the gastrointestinal tract. Young people living with IBD experience additional challenges in comparison to adults with the same condition. Lu and Markowitz (2010) note that the developmental and psychosocial changes unique to adolescence, including establishing autonomy and increased susceptibility to peer influence, make managing IBD in this age group more difficult. Engstrom (1992) established that psychiatric difficulties are more prevalent in young people with IBD than their healthier peers, or those living with diabetes or tension headaches. In a meta-analytic review of various chronic illnesses, IBD appeared to have the greatest impact on the psychological well-being of young people (Lavinge & Faier-Routman, 1992). Engstrom et al. (1999) propose that the findings of this research reflects the strong influence of the effects of the distinct clinical features of IBD, rather than the more general effects of living with a chronic illness as a young person.

² Enteral feeding delivers liquid nutrition through a catheter inserted directly into the gastrointestinal tract.

³ Parenteral nutrition provides nutrition intravenously.

⁴ Surgical opening where the end of small intestine is brought out on to surface of the skin, to which an external pouching system is attached to collect intestinal waste.

1.3.1.1 *Difference between IBD and other chronic illnesses*

Perhaps that which mostly distinguishes IBD from other types of chronic illness, such as cancer and diabetes, are IBD's associated symptoms; namely that of frequent diarrhoea and anal problems. The NACC (2011), describes IBD as, "An embarrassing illness" (p. 6) and highlight that, in general, people do not tend not to talk about bodily waste, bowel movements and toilet trips with others, even to people they would consider themselves close to. The embarrassment associated with their disease can be particularly hard for adolescents to manage. Young people may dread having to rush for the toilet. They may live in fear of having an accident, creating smells, and consequently being ridiculed by their peers (NACC, 2011). Others may avoid young people with IBD as they feel embarrassed themselves and do not know how to act or what to say (NACC, 2012). The unpredictability of IBD and its symptoms, may leave young people feeling great one day, and utterly drained and exhausted the next. Consequently, peers and teachers may find it difficult to comprehend that having IBD may prevent young people doing things that others may do, for instance feeling too tired to stay up late and have fun, or having difficulty concentrating in class. IBD may isolate such young people by causing them to miss school and certain school related activities, such as sports (Greenley et al., 2010).

The varying treatments received and their subsequent effects also distinguish IBD from young people's experience of other chronic illnesses. People are sometimes required to go on exclusion diets, to help identify foods that increase symptoms (NACC, 2011) or prescribed particular limited diets (e.g. liquid diets) when the disease flares up. The inability to eat similar foods to their peers may be a socially isolating experience for some young people, and may have a significant psychological effect (NACC, 2011; Diener, 2011). Reduced appetite and nutrient malabsorption may lead to young people with IBD being of a smaller stature than their peers, which may be an especially difficult experience during the phase of adolescence (Mackner et al., 2005). Steroids, a treatment typically used in IBD during flare-ups, present unique challenges for young people with IBD. Steroids may cause changes to young people's appearances. High doses of steroids can slow down growth, cause weight gain, rounding of the face, worsening of acne, increased body hair and moodiness (NACC, 2012). These

effects may leave young people feeling embarrassed or unattractive at a time when social validation and acceptance are of particular importance (NACC, 2011). In addition, steroids may make appearances deceiving. This is as, receiving steroidal treatment may contribute to young people looking well outwardly, even on days where they feel terrible.

Whilst previous studies have highlighted that living with IBD may be challenging for young people (e.g. Lavinge & Faier-Routman, 1992; Engstrom et al., 1999), these relatively old studies are few and far between, with most studies involving young people with IBD focused on investigating medical aspects of the condition rather than what it is like to live with and manage IBD. There is a dearth of studies that provide detailed information on living with and managing IBD, the type of information that qualitative studies are typically well placed to provide. In addition, where qualitative studies have been carried out, these have tended to focus more generally on quality of life for young people living with IBD (e.g. Lu and Markowitz, 2010) rather than focusing on specific aspects of living and managing IBD. Thus, little is known about what impact such experiences have on the psychological well-being of young people living with IBD. Therefore, focusing on a specific aspect of living and managing IBD as a young person, such as disclosure, will help to address a current gap in the literature and theoretical knowledge base.

1.4 'Invisible' illnesses and associated dilemmas

In referring to chronic health conditions, such as IBD, Joachim and Acorn (2000) make the distinction between 'visible' and 'invisible' illnesses. The term 'invisible' has been used to refer to chronic conditions where the symptoms associated with the condition may not be externally manifested and therefore may be less visible and harder for others to detect (Donoghue & Siegel, 1992; Joachim & Acorn, 2000; Stone, 2005). Conditions that are 'medically controlled', such as IBD, may be externally undetectable to others. Whilst IBD may be more visible to others when the disease flares up (e.g. looking thinner, paler), for the most part people affected by IBD tend to look well outwardly. In this way, IBD may be considered to be one such invisible condition.

Stone (2005) posits that, when compared to more visible conditions, invisible conditions present additional challenges. As well as being unobservable, symptoms of 'invisible' chronic illnesses tend to be immeasurable and subjective experiences (Donoghue & Siegel, 1992). This may make the difficulties that such conditions impose harder for others to recognise. Whilst the invisibility of these conditions may present certain challenges, it also offers people living with such illnesses a choice. Joachim and Acorn (2000) note that, because of the relative invisibility of their symptoms, people living with such invisible illnesses are more able to choose whether or not to tell others about their condition. For this reason, people with invisible illnesses, may have to make decisions relating to whether they wish to talk to others about their condition, how much information to give and who to tell, on a more frequent basis than those with more visible illnesses. These processes are often referred to as disclosure.

Researchers have suggested that people living with invisible chronic illnesses may find it difficult to talk about their conditions (Donoghue & Siegel, 1992; Joachim & Acorn, 2000; Stone, 2005; Diener, 2011). According to the NACC (2009), in spite of its prevalence, both IBD subtypes appear not to be relatively well known. The results of a public awareness survey carried out by the NACC (2009) revealed that the general population had lower levels of awareness of IBD when compared to illnesses such as diabetes, arthritis and HIV/Aids. When looking specifically at awareness of IBD, nearly a fifth of respondents had not heard of any of the IBD subtypes. This survey also indicated that awareness of IBD was lowest among the young (NACC, 2009).

Talking about the symptoms of IBD would involve talking about uncontrollable diarrhoea, flatulence and vomiting, amongst other things. In spite of these symptoms being very natural processes experienced by most people in their lives, they, particularly defecation, remain a source of disgust and private shame (Diener, 2011). This may make talking about IBD embarrassing for both the person living with IBD and others. Additionally, within most Western societies attaining and maintaining health is said to have become, "A metaphor for all that is good in life" (Crawford, 1980, p. 365), with ill-health being perceived as a

deviation from the norm. Consequently, Donoghue and Siegel (1992) note that most people would rather not hear about such symptoms and that society frequently imposes a, “Let’s not talk about it rule” (p. 44) on people with illnesses such as IBD. This may leave a person with IBD with less freedom to talk about their condition, symptoms and related experiences.

Previous research has shown that sharing condition information may result in a better quality of life for people living with invisible conditions (Jackson et al., 2010). However, it is likely that such disclosure can be challenging initially, although there is a paucity of research in this area to either confirm or dispute this. Focusing more specifically on both young people as a participant group, and IBD as a condition in its own right (two areas which have been largely ignored in the literature) will help to develop a detailed and developmentally-appropriate psychological understanding and conceptualisation of the experience of disclosing as a young person living with IBD. Eliciting such a detailed account of the experience of disclosing IBD to others and the elements that facilitate and hinder this process will improve professionals’ understanding of a key and potentially challenging area for young people living with an invisible condition, such as IBD, and how they manage this discretely.

1.5 Disclosure and Invisible illnesses

Disclosure, known also as ‘self-disclosure’ (Jourard, 1964), refers to the process of revealing authentic and intimate personal information to others (Derlega et al., 1993). Disclosure is described by Fisher (1984) as, “Verbal behaviour through which individuals truthfully, sincerely and intentionally communicate novel, ordinarily private information about themselves to one or more addressees” (p.278). As well as through verbal communication, disclosure may occur through non-verbal actions. In the case of chronic illness, behaviours such as repeatedly missing school or taking medications may constitute as such non-verbal self-disclosure. Disclosure is understood to be an on-going process, rather than being a single event (Dindia, 1998; Myers, 2004; Chaudoir & Fisher, 2010).

Self-disclosure is considered to be a central part of social interaction and is thought to be a key element in the building of interpersonal relationships

(Chaudoir & Fisher, 2010). Disclosure is also thought to be fundamental in the undertaking of impression formation and self-presentation, as disclosure may be utilised as a strategy to establish desired identities or avoid unwanted identities (Schlenker, 1980). Chaudoir and Fisher (2010) posit that decisions to disclose illness-related information may be influenced by factors on a number of different levels; the individual level (e.g. psychological distress), the dyadic level (e.g. increased trust), and the social contextual level (e.g. increased social awareness of such conditions). These levels are not mutually exclusive, and each level may relate to or affect another. Consequently, in choosing to disclose information to others, people may be trying to achieve both personal and social goals. In spite of the relatively high number of people living with chronic illnesses, research suggests that choosing to talk about an invisible condition may be complex and difficult (Dyck & Jongbloed, 2000; Joachim & Acorn, 2000; Fesko, 2001). Consequently, disclosure of chronic illness is described as being somewhat of a double edged sword, as it is possible to lose as well as gain support through the act of disclosure (Hays et al., 1992). Disclosure theorists (e.g. Altman & Taylor, 1973; Greene et al., 2006; Chaudoir & Fisher, 2010) concur on the premise that people choose to disclose on the basis of the associated physical and psychological costs and benefits of sharing such information. It is generally agreed that if the cost of disclosing personal information is considered to be greater than the anticipated rewards for sharing such information, then disclosure is unlikely to take place. As the reward-cost ratio increases, the likelihood of disclosure taking place increases along with it (Altman & Taylor, 1973). However, somewhat conversely, Troster (1997) states that individuals may choose to divulge information relating to a health condition to limit potential consequences associated with non-disclosure, a term he labelled 'preventative disclosure'.

The process of disclosing invisible conditions has been likened to the process of disclosure of sexual orientation experienced by gay, lesbian and bisexual individuals (GLB); a process commonly referred to as 'coming out' (Corrigan & Matthews, 2003; Myers, 2004). As the marks that signal homosexuality and invisible chronic illnesses are both not readily apparent, it is possible for both groups of individuals to hide aspects of themselves that they do not wish to share

with others (Corrigan & Matthews, 2003). Myers (2004) draws further parallels, explaining that both involve varying degrees of deviation from that which is taken to be the norm; both function on a continuum that may range from denial to self-acknowledgment to self-disclosure; both present potential risks in personal and social domains; and both may involve the experience of internalised guilt and shame.

In reviewing the literature, issues relating to the disclosure of invisible illnesses that appear the most prominent include: the evasion of stigma, the contexts of personal and social relationships, the desire for social and emotional support, reasons related to the illness itself, and the environment the people find themselves in. In the sections that follow, I will draw attention to these factors presenting IBD related research where available. In the absence of IBD related research, I will outline information gathered from studies carried out with young people or adults with other invisible illnesses.

1.5.1 The evasion of stigma

The most prominent topics in literature relating to the disclosure of health conditions relates to issues of stigma and social judgement. Many chronic illnesses have been linked to the experience of stigma including epilepsy, irritable bowel syndrome, prostate cancer, HIV/AIDS and mental health difficulties (Gray et al., 2000; Van Brakel, 2006; Weiss et al., 2006). In Goffman's (1968) seminal work on the topic, stigma is defined as possessing an attribute, behaviour, or reputation which is socially discrediting in a particular way. Stigmatised groups are often perceived to be inferior by groups that are in the majority and considered 'normal' (Goffman, 1974). This discreditation results in the disqualification of stigmatised groups from full social acceptance.

1.5.1.1 *Strategies to deal with stigma*

According to Goffman (1968), people who have the option of concealing potentially 'discreditable' aspects of themselves, have two strategies available in aiding them to minimise the experience of stigma, the first of which is 'covering'. Covering is an attempt to minimise the effect of the stigmatising condition (Goffman, 1968). Joachim and Acorn (2000) posited that covering is also utilised

as a strategy to help 'normal' individuals (those without health conditions) to feel comfortable around the person with the health condition. The other strategy is 'passing'. Passing involves the deliberate concealment of one's condition (Goffman, 1968), meaning that a person with particular condition would pass themselves off to others as someone without this condition. Both strategies are conceivably available to young people with IBD, as the symptoms of IBD are often unnoticeable or minimal (e.g. frequent diarrhoea, pain, fatigue).

The relationship between stigma and disclosure of invisible conditions

People may be reluctant to talk about such invisible conditions for fear of the consequences of the stigma associated with their condition. Illnesses may be stigmatising for various reasons. Physical and behavioural differences may make a person stand out from others and, consequently, may subject them to possible stigmatisation (Joachim & Acorn, 2000). People living with invisible conditions may be labelled by others as hypochondriacs, a label which itself is stigmatising (Ware, 1999). In society certain illnesses are also often misjudged and misunderstood by the general population. Many myths exist about illness symptoms and mortality, which often lead to overdramatisations of the seriousness of such conditions, which in turn creates greater fear and stigmatisation by others (Saylor & Yoder, 1998). Therefore, people's ability to disclose their invisible illnesses may be affected by the stigma surrounding the symptoms associated with their illness.

The social acceptability of an illness may also impact upon people's decisions to talk. In a study where participants were asked, hypothetically, if they would tell members of their family information relating to two chronic conditions (cancer and AIDS) participants were found to be more willing to disclose cancer as opposed to AIDS diagnoses (Greene, 2009). In a study of men with prostate cancer, whilst acknowledging that recent changes in societal attitudes had made it more conceivable for them to be candid about their illness and its effects (e.g. erectile dysfunction), men who sensed their diagnosis to be a threat to their social identities or as potentially inviting negative social judgements were found to be less prepared to disclose their condition (Gray et al., 2000).

Difficulty talking about chronic illnesses may also be associated with the assumption that other people will respond to disclosure in a negative or unhelpful manner (Joachim & Acorn, 2000). In studies with people with HIV, people cited fear of rejection and withdrawal of emotional and practical support as reasons for non-disclosure of their diagnosis (Gard, 1990; Simoni et al., 1995). People may also choose not to disclose for fear that others will be unable to comprehend or will misunderstand the physical and psychological challenges which they face (Stone, 2005). For instance, in a study examining the relationship between support and short-term recovery from breast surgery in women, participants reported feeling misunderstood when seeking support from others, participants reported feeling misunderstood (Funch & Mettlin, 1982). People living with invisible illnesses may also be put off talking about their condition as they may worry that people will not believe their condition is legitimate and therefore worthy of real concern (Roding et al., 2003).

People may choose to disclose information relating to their invisible illness depending on whether they believe this will lead to them being seen in a desirable or an undesired manner. For instance, people may withhold information about their condition, particularly information related to how they are feeling because they do not want to be perceived by others to be complainers or hypochondriacs (Donoghue & Siegel, 1992). Research carried out with people living with scleroderma found that people strategically decided when to tell others about their illness based on whether they believed they would receive positive reactions (Joachim & Acorn, 2003). Similarly, a study examining people with epilepsy's strategies for information management found that people were more likely to disclose their conditions if they expected that such disclosure would help them to exert a favourable influence on their interactional partner's opinion of them (Troster, 1997).

Whilst the fear of stigmatisation may suppress disclosure of invisible illnesses, Schneider and Conrad (1980) highlight that the perception of stigma by the person with the illness is key rather than whether or not people do actually hold such stigmatizing thoughts, as this is what will ultimately influence their decisions

to talk about their illness. This suggests that when people with invisible illnesses believe that they will be stigmatised they will be less likely to disclose their illness.

1.5.1.2 Stigma, IBD and disclosure

To date no research has explored the relationship between stigma, IBD and disclosure in adults or young people.

1.5.2 Personal and social relationship contexts

The decision to disclose an invisible illness, such as IBD, may be influenced within the context of personal and social relationships and obligations.

1.5.2.1 Personal relationships

Within the context of personal relationships, people may choose to talk about their invisible condition for a number of reasons including wanting to have a trusting and close relationship with their communication partner, wanting to share something in common, or to increase intimacy or closeness with another (Greene et al., 2006). Conversely, people may choose not to talk about their invisible illness for fear of losing relationships, because the other person is dissimilar to them, or because they feel that the information is not pertinent or significant to that relationship (Greene et al., 2006). In a study of men living with prostate cancer, participants demonstrated concerns that potential knowledge of their illness might frighten their friends and sever these relationships (Gray et al., 2000). Men in this study also commented that illness may introduce awkwardness into relationships, because they perceived that most individuals would not know how to be helpful to them (Gray et al., 2000). In addition, these men also cited people not having a clear practical need to know about their diagnosis as being a fundamental reason not to tell.

As suggested above, the quality of the relationship that one shares with another (e.g. the intimacy or contact anticipated) may determine if a person discloses to another about their invisible condition (Greene, 2009). Marks et al. (1992) found that HIV-positive men were more likely to disclose to significant others (i.e. parents, friends and lovers) than non-significant others (employers, religious leaders, landlords). Other studies carried out with HIV positive men indicate that

men who considered themselves to be well supported by family and friends, and thought it less probable that they would be harshly judged, were more prepared to disclose their HIV status (Straits-Troster et al., 1994). The quality of the relationship that a person shares with others may also influence how much illness related information is shared (Greene, 2009). According to the Social Penetration Theory (SPT), as relationships develop, communication between people transforms from non-intimate levels to deeper, more personal levels of communication (Altman & Taylor, 1973). SPT suggests that one would expect narrow breadth⁵ and shallow depth⁶ in the early stages of a relationship. However, as intimacy levels increase, a wider range of topics would be expected to be discussed, with many of these topics being talked about in greater detail (Altman & Taylor, 1973).

1.5.2.2 Personal relationships, IBD and disclosure

In relation to IBD related research, Lu and Markowitz (2011), in a paper discussing the unique challenges that adolescents with IBD face, postulate that young people with IBD may choose to disclose information about their condition to their peers to demonstrate that they trust that person and that they are at a particular stage in their relationship. No additional research has explored how the experience of talking about IBD might be influenced by the context of personal relationships, in either adults or young people.

1.5.2.3 Social relationships

Within the context of other social relationships people may choose to talk about their invisible condition because they feel a sense of responsibility to inform or have a desire to educate others (Greene et al., 2006). In a study with men with prostate cancer, the foremost reason cited for deciding who to disclose their diagnosis to was their sense of others' need or right to know (Gray et al., 2000). Similarly, Jackson et al. (2010) found that adult men with prostate cancer told others about their condition because they did not want to hide information from friends and family. In Gray et al. (2000)'s study some men were found to have shared their diagnosis of prostate cancer openly with people (friends and

⁵ Breadth refers to the quantity of topics a person feels able to discuss

⁶ Depth demonstrates the intimacy of information disclosed

colleagues) with the intention of helping others by educating them about prostate cancer and highlighting the importance of having screening tests. Similarly, a study exploring how HIV-positive positive activist women in South Africa negotiated the process of disclosing their diagnosis to their family found that participants disclosed their HIV status with the intention of educating loved-ones, or challenging inaccurate views and opinions (Almeleh, 2006).

Conversely, within the context of other social relationships, people may choose not to disclose their invisible illnesses because they may want to protect others from being upset or hurt, or because they believe that the other person will be unwilling or unable to be supportive or helpful (Greene et al., 2006). The former is a common concern cited in literature relating to experiences of adults with cancer, where talking about cancer is frequently found to be limited by people's desire to prevent emotionally burdening their families with their illness (Gray et al., 2000; Tam et al., 2003; Ashing-Giwa et al., 2004). People may therefore withhold information about their conditions to avoid feeling that they are imposing on others.

1.5.2.4 Social relationships, IBD and disclosure

To date, no research has explored how the experience of talking about IBD might be shaped by social relationships and obligations, in either adults or young people.

1.5.3 Social and emotional support

Whilst living with a chronic illness can be challenging, research suggests that this experience may be made more tolerable, physically and emotionally, if people feel able to share their experiences with others. The disclosure of health conditions is noted as presenting potential benefits, particularly that of increased access to practical, emotional and social support (Dilorio et al., 1996; Greene et al., 2006). In a study carried out by Jackson et al. (2010), men diagnosed with prostate cancer cited the desire to obtain the emotional support of others as influencing their decision to share information about their diagnosis. In a study investigating the disclosure of HIV status, potential disclosure-related benefits cited by adult participants included feeling loved and accepted and acquiring

additional information about their condition (Greene, 2009). In addition to gathering support from the people they confide in, disclosure may also alleviate adverse physical and psychological effects of suppression (Chaudoir et al., 2011). Davison et al. (2000) posited that talking to people with similar conditions at illness support groups helped people to make sense of their illnesses, highlighting this as another key source of support.

Whilst people may choose to disclose to achieve social, practical or emotional support, they may just as well choose not to talk about invisible illnesses for these same reasons. A study exploring men with prostate cancer and their decisions to talk (or not talk) to others about their diagnosis and condition indicated that, where possible, most men avoided disclosure (Gray et al., 2000). A key reason cited for men not disclosing prostate cancer included a low perceived need for support from others, particularly emotional support, even from their own spouses in some cases (Gray et al., 2000). Many of the men in the study did, however, feel thankful for and comforted by relatives and friends who did offer their support, but this was not usually perceived to be necessary (Gray et al., 2000).

In relation to IBD, only two studies appear to make reference to disclosure and access to social and emotional support. Research carried out by Janicke et al. (2008) investigating the association between peer victimisation, prosocial support, and treatment adherence in young people with IBD found peer support reduced the impact of hurtful peer interactions, such as bullying. In separate study examining the challenges experienced and strategies utilised by young people with IBD, Nicholas et al. (2007) found that the support and encouragement young people received from family and friends, enabled them to reframe their illness and to experience greater hope for the future.

1.5.4 Illness related reasons

Talking about an invisible illness may be facilitated or inhibited by issues relating to the illness itself. In the sections that follow I will discuss this in relation to prognosis and course of illness, illness management, the impact of disclosure on emotional and physical well-being and the desire to live a 'normal life'.

1.5.4.1 Prognosis and course of an illness

The prognosis and course of an illness may influence people's decisions to disclose. Uncertainty is considered to be a dominant component of people's illness experiences (Mishel & Clayton, 2003; Hogan & Brashers, 2009). Due to its relapsing and remitting course, for many people living with a fluctuating illness like IBD, this may involve living in a state of uncertainty. Such uncertainty may cause people to want to talk to others about their chronic illnesses (Checton & Greene, 2012). However, this same experience of uncertainty may leave people feeling unsure as to whether they should communicate information relating to their illness and how they should do this (Goldsmith, 2009). In a study of older adults managing heart-related conditions, Checton and Greene (2012) found that appraisals of symptom and prognosis uncertainty affected communication with people's partners in different ways. Whilst prognosis uncertainty was found to be positively associated with communicating with one's partner, symptom uncertainty was found to be negatively associated with the frequency of communication about their heart conditions (Checton & Greene, 2012).

This study highlights uncertainty about symptoms, as opposed to uncertainty about prognosis, as being a more salient predictor of people's ability to talk to others about their health conditions. Conversely, a study with men with prostate cancer found that those who discovered having metastatic disease, or whose condition post-surgery remained uncertain, spoke of finding it less feasible to avoid talking to others about their condition (Gray et al., 2000). This may be related to people's condition and associated symptoms becoming potentially more visible to others, the sicker they become (Hays et al., 1993; Mansergh et al., 1995). Consequently, people may be more inclined to disclose that which they may be incapable of hiding successfully (Gray et al., 2000).

1.5.4.2 Disclosure and illness-management

Whilst invisible illnesses, such as IBD, are concealable, young people who choose to hide such a condition run the risk of their illness being revealed to others at any time (Dyson et al., 2010). Somatic signs, prolonged absences from school due to illness, and engaging in preventative measures (e.g. restricted diet,

medication) may be sufficient for others to notice that the young person is 'different' from their peers and may invite unwelcome attention (Dyson et al., 2010). A study examining information management strategies used by adults with epilepsy suggests that willingness to disclose an invisible illness increases as the perceived likelihood of people detecting or finding out about their illness increases (Troster, 1997). The effective management of treatments and routines may necessitate disclosure (Beatty, 2001). Certain health conditions may involve illness-specific or treatment specific behaviours that would be challenging to hide from others (Munir et al., 2005). Consequently, disclosure may be precipitated by the use of medication, frequent absences from school to visit specialists or to receive treatment in hospitals as an outpatient and/or inpatient (Beatty, 2001; Munir et al., 2005). Therefore, whilst young people may express a preference to avoid discussing their invisible illnesses, this choice may be influenced in part out of necessity.

1.5.4.3 Impact of disclosure on emotional and physical well-being

Hays et al. (1993) note that concealing a HIV diagnosis can not only lead to problems in health and treatment adherence, but could contribute to their significant others experiencing distress, particularly if disclosure occurs at a time when the individual is unwell. Additionally, Renfrew (2004) postulated that 'passing' can have further negative effects and that concealing a central identity may come at an emotional cost.

1.5.4.4 Desire to live a 'normal' life

People may also choose not to talk to others about their invisible illnesses in an attempt to lead what they perceive to be as 'normal' a life as possible. Contrary to the prevailing stigma literature, a study carried out with young people living with cystic fibrosis found that disclosure-related decisions did not reflect feelings of shame or pride, but that disclosure strategies were chosen on the basis of their ability to enable these young people to live 'ordinary' lifestyles (Admi, 1995). Gray et al. (2000)'s study with men living with prostate cancer found that men's disclosure of their illness reduced over time and that this decline appeared to coincide with the frequently spoken wish to, as much as possible, have their lives revert back to normal. Therefore, not talking to others may be perceived by

people with invisible illnesses to be a strategy which might help them not to feel consumed by their illnesses (Gray et al., 2000).

1.5.4.5 Illness related reasons, IBD and disclosure

At present no research has explored how issues relating to IBD, as a condition in its own right, might affect the experience of talking about IBD, in either adults or young people.

1.5.5 The environment

The situation and environment that a person finds themselves in can also be influential in decisions to disclose information about illness (Greene et al., 2006). Lightfoot et al. (1999) argue, as most young people spend a considerable portion of their lives at school, that it is imperative to recognise the experience of living with a chronic illness within the context of school life.

1.5.5.1 School and disclosure

Similar to IBD, sickle cell disorder (SCD) has a variable and unpredictable course and has symptoms which are largely invisible to others (e.g. fatigue, pain, palpitations). Dyson et al. (2010), in a mixed methods study carried out in the UK, examined young people with SCD's disclosure-related decisions in relation to fellow pupils and teachers whilst in primary, secondary and post-secondary education . They found most young people favoured disclosing SCD to their teachers (Dyson et al., 2010). This preference was cited as relating to young people wanting teachers to make allowances for school absences or periods of illness and for them to know what actions to take during spells of illness (Dyson et al., 2010). However, Dyson et al., (2010) also noted some participants as disagreeing and stated that telling teachers carried significant disadvantages, including teacher's caring attitudes attracting unwanted attention (e.g. by allowing them to do things not normally permitted, such as toilet-breaks during class), and teachers displaying disabling reactions and attitudes (e.g. being called "drama queens" for complaining about pain).

In terms of disclosing to peers, this study revealed that young people with SCD's feelings were varied. Those in favour of disclosure viewed talking about their

SCD as a positive and important strategy for negotiating school-life with their condition, and related negative acts and attitudes, such as teasing, to ignorance on the part of their peers (Dyson et al., 2010). Views against disclosure related predominately to perceived, potential or actual teasing and bullying, fears that information would be haphazardly spread to others, and worries that other young people would be unable to understand what living with the condition entailed (Dyson et al., 2010). Participants identified as being uncertain about disclosing their condition at school described experiencing a tension between acknowledging the reality of the chronic condition they lived with, and not wanting SCD to be a dominant part of their identity (Dyson et al., 2010). Other reasons cited for feelings of ambivalence included the expectation that peers would have differing reactions. Reactions discussed by participants included peers enquiring more about their condition in a positive way, or peers 'turning their backs' on them (Dyson et al., 2010).

In a separate qualitative study investigating the impact of a range of illnesses and disabilities (visible and invisible) on young people's school lives, participants were found to have mixed views in relation to whether they wanted peers to know about their conditions (Lightfoot et al., 1999). Reasons for wanting peers to know included wanting their peers to know what to expect and what to do in an emergency, and for peers to be more understanding of their situation (Lightfoot et al., 1999). Reasons cited for young people not wanting peers to know about their conditions included peers not needing to know and wanting to maintain a sense of privacy (Lightfoot et al., 1999). Suris et al. (2004) in reviewing the reciprocal effects of chronic conditions (visible and invisible) on adolescent development wrote at length about the impact of chronic health on schooling. They found that most participants, in attempt to not stand out from others, did not share any information about their condition. Similar to research carried out with adults, Suris et al. (2004) suggested that adolescents and their parents may be disinclined to disclose their illnesses for fear of being labelled and stigmatised at school.

1.5.5.2 *Transition from primary to secondary school*

In the UK most pupils advance from primary to secondary school at age 11⁷. For many young people, this transition represents a significant life-event and has been noted as a stage that presents particular challenges and threats to adolescents' well-being (Seidman et al, 1994; Sirsch, 2003). Whilst adolescence itself is a social construct, one could argue that in the UK this transition to secondary school overlaps with children's transition to adolescence. Young people with chronic conditions entering secondary school may, therefore, find themselves negotiating new school relations, within the context of being an adolescent living with a chronic illness (Dyson et al., 2010).

The transition to secondary school typically involves young people leaving smaller schools to form part of bigger secondary schools, and consequently wider peer and professional systems. Young people with invisible chronic illnesses may therefore find themselves meeting new people, peers and professionals alike, who may be unaware of their condition. Lesch et al. (2007) note that, unlike adults, HIV-infected children commonly have little control over the disclosure of their condition to others as the flow of information is controlled by their caregivers. Similarly, the study exploring young people's disclosure of SCD (outlined in section 1.5.5.1) found that disclosure to teachers was typically mediated through mother's informing schools about their child's condition, when the child was at an age where they were thought to be unable to communicate this idea for themselves (Dyson et al., 2010). Accordingly, whilst in primary school, young people diagnosed with chronic conditions, such as IBD, may be protected from the responsibility of disclosing their condition. As suggested in these studies, parents of such young people may disclose their condition on their children's behalf. Consequently, peers at primary school may grow up knowing that a certain young person within their peer group has IBD. However, once a young person starts secondary school this may change.

Transition to secondary school typically involves contact with larger groups of peers and school professionals than previously experienced at primary school.

⁷ Age on 31st August (before the school year)

For young people with IBD this may involve interacting with new people, unaware of their condition. In a study exploring young people's views of the support they received in mainstream schools in relation to their chronic illnesses, participants listed peer curiosity in relation to their conditions as being challenging to manage, particularly at the beginning of the school year when the influx of new students was common (Lightfoot et al., 1999). This study suggests that young people with invisible illnesses, such as IBD, who have moved from primary to secondary school, may be faced with increased decisions related to disclosure of their illness. Adding to this, those who are newly diagnosed may also find themselves having to make decisions related to the disclosure of their illness for the first time. Consequently, young people may find themselves juggling two new experiences; self-disclosure and transitioning to secondary school, each presenting their own respective potential opportunities and challenges. At present the experience of talking about IBD as a young person, within the context of having transitioned from primary to secondary school, has not been explored.

1.5.5.3 School, IBD and disclosure

No research to date has explored the experience of talking about IBD within the context of school.

1.5.6 Psychological and physical implications of disclosure of invisible illnesses

1.5.6.1 Psychological distress

Stress is commonly linked to negative psychological outcomes, as well as increases in somatic complaints (DeLongis et al., 1988). One study carried out with 'normal' school-aged adolescents identified relational victimisation from peers (e.g. bullying, as being a distinctive predictor of increased somatic complaints (Nixon et al., 2011). Whilst defining 'stress' as a construct may be difficult as this is largely dependent on personal perceptions, coping strategies and personal experiences (Neuman, 2007), it is generally acknowledged that perceived psychological stress levels may be linked to the exacerbation of IBD (Saed et al., 2002). Studies carried out with adults living with other invisible illnesses (e.g. HIV) found condition disclosure to be a recurrent and significant stressor for individuals (Holt et al., 1998). As highlighted above, the period of transition from primary to secondary school is acknowledged as being a time

when young people may experience increased stress (Seidman et al, 1994; Sirsch, 2003). Therefore, one might argue that the experience of stress associated with disclosure may potentially be exacerbated by this period of transition. However, due to the paucity of research in this area, it is not currently possible to make this implication. Exploring the experience of disclosure of IBD in young people during this potentially vulnerable time is of increased clinical importance as this may offer a detailed understanding which in turn would inform tailored interventions aimed at reducing such stress, thereby improving these young people's physical as well as psychological health.

1.5.6.2 Social relationships

Disclosure is considered an integral part of every-day social interaction (Herek et al., 1996). Young people at school will disclose information about themselves on a daily basis, for instance, their hobbies, favourite subjects at school or sports teams. As highlighted in section 1.5.2 above, a wide range of literature suggests that disclosure is an integral part of forming and maintaining social relationships (Altman & Taylor, 1973; Greene et al., 2006; Lu & Markowitz, 2011). Many studies with young people note that having a sense of meaningful connection with peers as being a strong predictor of psychological well-being during adolescence (Qualter & Munn, 2002). For instance, friendships are commonly noted as providing people with valuable sources of self-esteem (Bandura, 1982; Hoffman et al., 1993). Additionally, as noted in section 1.5.3, disclosure can help people feel loved and accepted (Greene, 2009). This finding might suggest that those young people who are unable to disclose, may risk feeling unaccepted and isolated. Indeed, many studies have noted consistent non-disclosure as being related to experiences of isolation and loneliness (Franzoi & Davis, 1985; Stokes, 1987). Therefore for a young person with IBD, the importance placed upon the need for social belonging during adolescence (Hall et al., 2007) coupled with the key role disclosure plays in relationship formation, an inability to disclose their illness to peers at school may impact on their ability to form and sustain key friendships, which in turn may have negative effects on their psychological health.

1.5.6.3 Identity Formation

Given the role that peer interaction is said to play in identity formation during the period of adolescence (Erikson, 1968; refer to section 1.2), the act of disclosure takes on further psychological importance, by means of its role in the process of self-discovery. Erikson notes that failure to achieve a sense of self during this developmental stage may lead to a state of 'identity crisis' (Erikson, 1968). Such a crisis of identity may leave young people struggling to 'find themselves'. Consequently, to address this gap, young people may seek out negative identities, for instance ones involving substance misuse or crime or may find it difficult to make defining choices about their futures (Erikson, 1968). This identity crisis, together with the potential loss of their pre-illness selves said to be experienced by adults with chronic illnesses (Charmaz, 1983; refer to section 1.2) may leave young people with IBD at this developmental stage particularly vulnerable psychologically. Consequently, the ability to disclose invisible illnesses such as IBD, particularly during adolescence, will be paramount to young people's overall psychological development and well-being.

1.5.6.4 Illness management and support

In addition to alleviating the psychological stresses associated with suppressing an invisible identity (Chaudoir et al., 2011), disclosing IBD to peers and professionals at school may also serve to alleviate the physical costs of concealing an invisible condition. Concealment of invisible illnesses in adults has been linked to difficulties in adhering to health-related behaviours (Hays et al., 1993). Treatment regimes that are more visible to others at school (e.g. restrictive and liquid diets, steroidal treatment which may result in rounding of the face and severe acne) may make the option of not disclosing less likely for young people with IBD in secondary school. Given adolescents commonly cited desire for social belonging and acceptance, young people with IBD who have not disclosed to others at school may purposefully omit all or part of their treatments regimes in an attempt to 'fit in' with their peers. Consequently, young people's inability to disclose to people at school may place them at increased risk of engaging in health detracting behaviours.

Whilst living with a chronic illness can be challenging (Sirois, 2009), research has shown that this experience may be made more tolerable if people feel able to share their experiences with others. Disclosure of a health condition may present potential benefits, such as increased access to practical and social support (Dilorio et al., 1996). Social support has been found to play a significant part in mediating between stress and health (Kulik & Mahler, 1989). In particular, peer support has been linked to better psychosocial adjustment in young people with chronic illness, as well as improved adherence to treatment (Bearman & LaGreca, 2002). Disclosing their condition to others may offer young people with IBD increased access to peer support which may be of particular benefit to young people at this developmental stage. For instance, peer support has been noted as helping to reduce the impact of hurtful common peer interactions at school, such as bullying (Janicke et al., 2008). However, such peer support, and any potentially positive clinical and psychological effects associated with it, will only be available to young people with IBD who feel able to disclose to others.

1.5.6.5 (In)dependence from parental figures

As a developmental stage, adolescence is typically associated with increased independence from parents as young people separate from parental figures in search of their own identities (Kroger, 1985). However, parental involvement in aspects of adolescents' lives which ordinarily would be ignored is an observation commonly noted in the management of chronic paediatric condition, such as diabetes (Wysocki, 1993). As highlighted above (section 1.5.6.4), disclosure plays a key role in the management of invisible illnesses such as IBD. Studies indicate that the disclosure of paediatric invisible illnesses, such as HIV and SCD, is typically managed by parents as either parents or young people themselves feel incapable of following through with this (Lesch et al., 2007; Dyson et al., 2010). This raises questions as to the implications this has on how young people manage such seemingly competing demands; the social expectations of increased independence from one's parents as an adolescent, as well as potentially being deemed or feeling unable to manage disclosing their own IBD. At present, the implications of these seemingly opposing demands and how this is managed by young people with IBD within the context of the key role which disclosure plays as part of illness management remains unclear.

1.6 Gap in the Literature

As the review of literature in the sections above indicates, there is a dearth of research into the experience of IBD from young people's perspectives. Daniel (2002) describes existing accounts of young people's experiences of IBD as being predominantly anecdotal and founded upon the accounts of health professionals. When it comes to examining young people's experiences of chronic illness more generally, there also appears to be a paucity of research, with parents or guardians often being invited to speak on their child's behalf (Guell, 2007). Consequently, the conceptual and theoretical understanding of chronic illness in young people may be founded on the perception of adults rather than the perception of young people themselves. Furthermore, Lightfoot et al. (1999) note that few studies have directly sought the views of young people living with chronic conditions within the context of school life.

The review of literature undertaken for this present study revealed very little research focused on the experience of young people disclosing invisible health conditions in general. Previous research focusing on other invisible conditions has shown that making decisions to disclose can be challenging; these challenges could plausibly be exacerbated by school transition. By aiming to elicit the experience of disclosing IBD to others and the elements that facilitate and hinder this process this research will improve professionals' understanding of a key challenging area for young people with an invisible condition such as IBD and how they manage this discretely. The findings can also be used to inform support services for young people with IBD, within hospitals and locally. Previous research has also shown that sharing condition information may result in a better quality of life (Jackson et al., 2010), however, there is a paucity of research in this area to either confirm or dispute this for young people living with an invisible condition such as IBD.

Whilst there is an abundance of research into the medical management and control of IBD, this review highlights that other aspects of illness management, such as disclosure, and the psychological implications of these aspects have been largely ignored. To date, no research has specifically looked in to the

experience of disclosure for people living with IBD of any age. As highlighted above, IBD differs in many ways to other invisible conditions. Hence, whilst past research has looked at the disclosure of other invisible illnesses, it is not appropriate to simply extrapolate from other invisible illnesses to IBD. Therefore, it is important that the experience of young people disclosing IBD is explored in its own right. In focusing on the experiences of young people with IBD following their transition from primary to secondary school, this study aims to provide a detailed insight into young people's experiences of talking about their IBD, a condition that may be considered to be 'invisible', at this seemingly important and potentially vulnerable stage of their lives.

Eliciting such a detailed account of the experience of disclosing IBD to others and the elements that facilitate and hinder this process will improve professionals' understanding of a key and potentially challenging area for young people living with an invisible condition such as IBD and how they manage this discretely. This information may be used to develop strategies supporting the process of disclosure further amongst young people with IBD. This may be achieved via future therapeutic work and recommendations of ways in which professionals may facilitate discussion of this condition. This information may also be used to inform support NHS and other services supporting young people with IBD. Additionally, such information will increase the awareness of the challenges associated with disclosure of invisible conditions, aiming to increase effective support for young people with invisible conditions by identifying their key concerns.

1.7 Summary, aims of intended study and research questions

The studies cited in the sections above suggest that the process of making disclosure-related decisions is complex and influenced by a variety of factors. Talking about IBD as a young person approaching adolescence may be further compounded by a variety of physiological, psychological and social variables. When deciding to talk about IBD young people may, therefore, find themselves having to balance the need to obtain potential benefits associated with disclosure, whilst attempting to avoid negative consequences that may be derived from sharing such information.

As highlighted by the literature reviewed in this chapter, the current literature on young people with IBD does not appear to shed much light on young people's experience of this. This study will ask seven young people aged 12 to 13, diagnosed with IBD prior to transitioning to secondary school, to discuss their experiences of talking to people at school (peers and staff) about their condition, following their transition from primary to secondary school. The immediate aim of the study is to gain an understanding of what it is like to disclose and talk about IBD as a young person following this transition. The research questions are as follows:

- 1) How do young people with IBD manage the disclosure of their condition?
- 2) How are young people's experience of disclosing and talking about IBD affected by their transition from primary to secondary school?
- 3) What facilitates and hinders talking about IBD as a young person living with this condition?

CHAPTER TWO: METHODOLOGY

2.1 A qualitative approach

As highlighted in Chapter 1 (section 1.6), when it comes to examining young people's experiences of chronic illness, particularly invisible illnesses such as IBD, there is a paucity of research. Qualitative approaches are well placed to explore novel areas of research (Barker et al., 2002). Whilst structured materials, such as multiple choice questionnaires, could have been used in this study it was felt that the existing research could be enriched by a qualitative study, whose intentions are to explore, describe and interpret the personal and social experiences of individuals (Smith, 2008). This decision was also supported by concerns that structured measures may not be sensitive enough to encapsulate the experiences of young people with chronic illnesses (Woodgate, 1998). Such measures may have also diminished the opportunity for young people to talk about matters of personal concern (Miller, 1999). A qualitative approach also seemed to fit with the study's intentions of understanding a relatively small sample of participants' own experiences in depth, instead of testing a predetermined hypothesis using a large number of participants (Smith, 2008).

2.2 Interpretative Phenomenological Analysis (IPA)

IPA is an approach to qualitative enquiry committed to exploring in detail how individuals make sense of significant life experiences (Smith & Osborn, 2008). The meanings specific experiences, states and events hold for participants are viewed to be the main currency for IPA studies (Smith & Osborn, 2008). IPA positions participants as the experts on their experiences who, through the telling of their own stories in their own words, extend to the researcher an insight into their feelings, thoughts and commitments (Reid et al., 2005). Epistemologically, IPA is generally said to occupy a position between critical realism and contextual constructivism. In this study a reflexive approach, alongside a broadly critical realist epistemology were adopted (Willig, 2001). This position permits one to recognise the experiences of young people disclosing IBD as being 'real', whilst acknowledging that there is no single 'true' way of understanding such experiences. The three key philosophical underpinnings of IPA are phenomenology, hermeneutics and idiography.

The first theoretical underpinning of IPA is phenomenology, the philosophical study of what an experience is like. Husserl's phenomenological transcendental philosophy emphasised the importance of focusing on experience and individuals' own understandings of their experiences (Willig, 2001). This notion was further developed by Heidegger, Merleau-Ponty and Sartre, who proposed that people are embedded in the world and do not live in isolation. Therefore, individual's experiences of living in the world were understood to influence individuals' perceptions of their own lives and experiences. Consistent with its phenomenological roots, IPA is concerned with obtaining what Conrad (1987) terms an 'insider's perspective'. It is interested in trying to understand events and objects from a participant's point of view, typically through the medium of interviews, with the intention of getting, "Close to the participant's personal world" (Smith et al., 1999, p. 218).

The second major influence upon IPA is hermeneutics, the theory of interpretation. Within hermeneutics, the complexity of the relationship between that which is interpreted and the interpreter is acknowledged. Influenced by Heidegger's philosophy, IPA notes that access to a participant's experiences depend upon, and are affected by, the researcher's own foreunderstandings (Smith et al., 2009). Therefore, research in IPA is conceptualised to be a dynamic process, within which the researcher plays an active role (Smith & Osborn, 2008). This process is referred to as a 'double hermeneutic', meaning that in IPA studies a researcher is trying to make sense of a participant trying to make sense of their lived experience, through a process of interpretative activity (Smith & Osborn, 2008). As all discoveries made are shaped in part by the researcher and participant relationship, IPA stresses the importance of remaining open to one's own biases and preconceptions during the process of engaging with new phenomena (Smith et al., 2009). Consequently, to preserve transparency, researcher reflexivity is promoted.

Another key contribution of Hermeneutic philosophy to IPA research is the concept of the hermeneutic circle. This concept is utilised to stress the significance of the dynamic relationship between the part and the whole, at a range of levels (Smith et al., 2009). Smith et al. (2009) elaborate stating that for a

researcher to gain an understanding of a given part, they must look to the whole; and to gain an understanding of the whole, they must also look to the parts. Consequently, within IPA the production of an interpretative account is perceived to be an iterative rather than a linear process (Moran, 2000; Smith et al., 2009). An IPA researcher is therefore required to move back and forth through various parts of the data (i.e. through these different levels) to acquire an understanding of a given text (Smith et al., 2009).

Idiography is the final major theoretical underpinning of IPA. Unlike nomothetic approaches which are concerned with claims at a group level and focus upon the generalisability of findings, idiographic approaches, such as IPA, are concerned with the particular. Such ideographic approaches are concerned with understanding the meaning of individual life based on the experiences and perspectives of a small group of specific people, who find themselves in a particular context (Smith et al., 2009). Based upon these principles, the aim of an IPA study is to describe, in as much detail as possible, the perceptions and understandings of a small and particular group of people as opposed to prematurely making more general claims (Smith & Osborn, 2008).

2.2.1 Reasons for choosing IPA

The phenomenological nature of IPA is in accordance with the objective of this research, namely, to gain an insider's perspective into how young people with IBD experience talking about their invisible condition following their transition from primary to secondary school. IPA's idiographic disposition fits well with the study's aim to explore in detail the lived experiences of a small group of young participants. As a methodology, IPA is considered to be particularly relevant to both the clinical and health psychology field (Reid et al., 2005; Brocki & Wearden, 2006). IPA allows for the detailed exploration of participants' subjective experiences, and facilitates a description and understanding of how participants, "Perceive and make sense of their lived experiences of illness" (Eatough & Smith, 2008, p.186), thereby adding to the biopsychosocial perspectives on health (Reid et al., 2005). Even though broad generalisations are not possible with IPA, commonalities across accounts along with the researcher's analytic commentary

may present valuable insights with widespread implications (Smith, 2004; Reid et al., 2005). This fits with the intentions of exploring an area where research with young people has been limited or based upon the perceptions of adults (Shaw, 2001). IPA also seemed appropriate given that the role and influence of the researcher in how interpretations and conclusions are attained are explicitly acknowledged through the notion of the double hermeneutic. This seemed particularly important and relevant given my own experiences of living with IBD (see section 2.6).

2.2.2 IPA as opposed to other qualitative methodologies

Whilst hermeneutic phenomenology, descriptive phenomenology and IPA all focus on individuals' lived experiences, IPA was chosen over both. Although it appears to be quite similar to hermeneutic phenomenology, IPA offers a more structured method of analysis (Finlay, 2011). IPA was chosen over a more descriptive phenomenological approach due to its interpretative element, along with its use of hermeneutics in understanding and interpreting participants' sense-making. This use of hermeneutics in understanding how individuals make sense of their lived experience, along with the more detailed engagement required when analysing data whilst utilising IPA influenced the decision not to use thematic analysis and content analysis. In spite of their similar focus on people's meaning making, grounded theory was deemed inappropriate as it is more inclined to focus on processes of social phenomena rather than the psychological processes relating to how people make sense of a particular phenomenon (Willig, 2001).

Discourse Analysis was also felt unsuitable owing to its detailed focus on the function language plays in constructing social reality (Willig, 2008). This is as the study's aim of understanding young peoples' particular lived experiences of talking about IBD did not appear to fit with discourse analysis' aim of analysing the discursive effects of participants talking about a particular experience from a particular context. Narrative analysis is interested in, "The ways in which people make and use stories to interpret the world" (Lawler, 2002, p.242). Whilst both appear to operate on similar levels, IPA was chosen because of narrative analysis' relatively new application to the field of psychology. IPA also presented

greater opportunities for expert supervision and attending specific training and workshops.

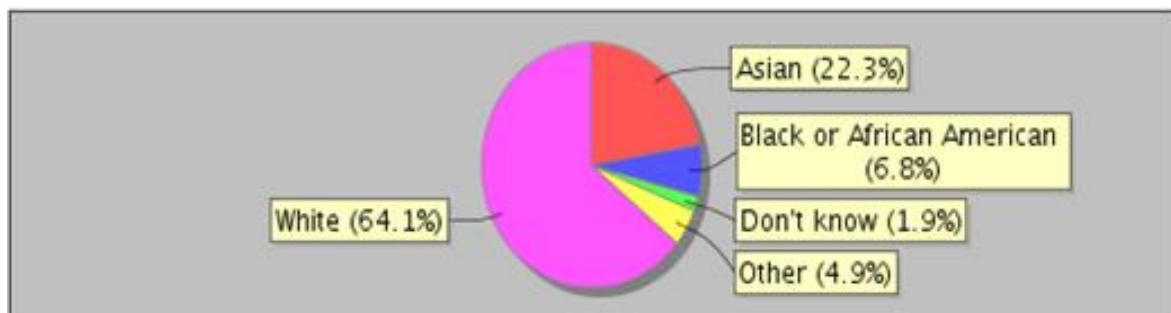
2.3 Method

2.3.1 Participants

2.3.1.1 *Context of the study*

Participants were recruited from an outpatient paediatric IBD clinic attached to a children's hospital in the South East of England. The clinic consists of three paediatric consultant gastroenterologists, two clinical nurse specialists, with input from a dietician and clinical psychologist. The clinic's current IBD caseload is 266 children and adolescents aged 4-16 years, with a ratio of 110 girls to 156 boys. 48.1% have a diagnosis of Crohn's disease, 25.6% have ulcerative colitis, with a further 26.3% having indeterminate colitis⁸ or IBD like diagnoses. The ethnicity of the young people with IBD under the care of this team is presented in Figure 1.

Figure 1. Ethnicity of young people under the care of the source of sample



2.3.1.2 *Inclusion and exclusion criteria*

The clinic identified potential participants according to the following criteria:

- Females and males with IBD. This included people diagnosed with Crohn's disease or ulcerative colitis.

⁸ Term used for a colitis that has features of both Crohn's disease and ulcerative colitis.

- Individuals who experienced moderate⁹ episodes of IBD. Individuals with an ileostomy or colostomy were excluded to avoid a skewed sample.
- Young people aged 12-13 and in Year 8 at secondary school, to obtain as homogenous a sample as possible.
- Individuals who had received a diagnosis of IBD at least 12 months prior to transitioning from primary to secondary school, to allow participants time to adjustment to the diagnosis.
- Individuals who had no additional diagnosis of a chronic, severe medical or psychological condition.
- Individuals who had experience of transitioning from a UK primary school to UK secondary school. Participants had to have attended a UK primary school at least 6 months prior to transition.
- Young people who were English speaking. Given the emphasis placed on language in qualitative studies non-English speaking participants were excluded for fear that the richness and meaning of language might become lost in the process of translation.

2.3.1.3 *The sample*

At the time of the study, the team had 52 young people with IBD aged between 12 and 13 years on their caseload. Ten of these young people met the inclusion criteria and were identified by the team. Seven chose to participate in the study. Participants were four males and three females who had a diagnosis of either Crohn's disease or ulcerative colitis. Details of the participants are summarised in Table 1 in chapter 3 (p.35).

2.3.2 Procedures

Ethical approval to conduct this study was sought and granted by the University of East London ethics committee, the Bromley NHS research and ethics committee, and the hospital's own clinical research adoptions committee (Appendix 2). Following this, the database manager of the gastroenterology team identified potential participants according to the criteria listed in section 2.3.1.2.

⁹ For the purpose of this study moderate flare-ups were considered to require participants needing to open their bowels up to five times a day.

Potential participants and their parents were initially contacted and informed of the research by members of their clinical team. All contacted expressed an initial interest in participating in the study and were sent an invitation letter (Appendix 3) and two information sheets, one for parents and guardians and another for the young people (Appendices 4 and 5). I contacted participants and their parents by phone two weeks later to answer further questions and ascertain verbal consent and assent. Following this, an interview date was set. At this point, three participants choose not to participate. Participants were interviewed on one occasion in private rooms on the hospital's premises. Where possible, interviews were scheduled to coincide with a participant's pre-existing outpatient appointments. The young people were interviewed on their own, without their parents in the room. Interviews lasted between 40 and 70 minutes, depending on the individual level of detail recalled by the participant. Following the interview, participants were debriefed and given the opportunity to reflect on their experiences of the interview.

2.3.3 Data Collection

Before carrying out the interviews I contemplated how young people, most of who were male, might feel about meeting with an older professional woman to share their experiences of talking about IBD at school. I also thought about the potential paradox in doing this; that I was asking young people to talk to me (a relative stranger) about their experiences of talking about IBD. Presuming that this might be a challenging experience for some, I chose to initiate interviews by openly reflecting upon this with participants.

2.3.3.1 *Preliminaries*

Following introductions, I ensured that both the participants and their parents had read the relevant information sheets and offered them the opportunity to re-read these. Following this, participants and their parents were asked if they had any further questions. Participants were reminded that their participation was voluntary and that they had the right to from the study at any point without their clinical care being affected. Issues relating to confidentiality were explained thoroughly and participants were reminded that they could request a break or end

the interview at any time. Participants were also told that the interview would be recorded. Parents were asked to sign consent forms (Appendix 6) whilst participants were asked to sign assent forms (Appendix 7) prior to interviews beginning. The structure of the interview was also explained.

2.3.3.2 *Semi-structured interviews*

Data was collected using semi-structured interviews. This method is recommended for IPA studies as they permit the researcher to enter, as far as is possible, a participant's psychological and social world (Smith and Osborn, 2008). The interview schedule (Appendix 8) was developed following relevant literature and guidance on constructing such schedules (e.g. Smith & Osborn, 2008). Whilst the interview schedule offered a framework for the interviews, this was not strictly adhered to in order to allow novel perspectives to emerge and, so as to privilege the experiences that participants felt were important to them (Bannister et al., 1994). Utilising such a flexible approach positioned participants as experts on their experiences and facilitated their ability to tell their own stories, using their own words (Smith et al., 1997). This was of particular importance given that phenomenological approaches are concerned with, "An individual's personal perception or account" (Smith et al., 1999, p. 218). Additionally, it was hoped that such a flexible approach would foster informal, flexible conversations, which in turn would facilitate rapport and produce richer data (Smith, 1996). Interviews were digitally recorded and then transcribed. Identifying information was disguised or expunged.

2.4 Data analysis

The data was analysed using IPA, guided by the four procedural steps outlined by Willig (2001) and Smith, et al. (2009) and literature by Elliot et al. (1999) and Yardley (2008) on quality in qualitative research (see section 2.5). It is important to note that there is no single, definitive way of conducting IPA, and that analysing data is a personal process which involves an unavoidable degree of subjectivity (Willig, 2001; Smith & Osborn, 2008). During this phase, transcripts were analysed individually in turn to preserve the ideographic process and supervision was received from an experienced qualitative researcher.

2.4.1 Approach to analysis

2.4.1.1 *Initial encounter with the text*

The process of entering the participant's world began by repeatedly listening to individual accounts during transcription. This was followed-up by reading each transcript several times. Notes were made in the right hand margin to record my initial thoughts and observations in response to the text (Appendix 9). In addition to summaries of that which was said, notes included comments on associations, variances, absences and inconsistencies observed, along with comments on language use and questions raised (Willig, 2001).

2.4.1.2 *Initial exploratory coding*

Transcripts were then re-read and the left hand margin was used to tentatively note emerging themes (Appendix 9). Moving to a higher and more interpretative level of abstraction, the initial notes were converted into succinct phrases with the intention of capturing the quality of that which was found in the text (Smith et al., 1999). This was completed by paying particular attention to three main areas of interpretation: the descriptive¹⁰, the linguistic¹¹, and the conceptual¹². Emergent themes were listed chronologically and collated in a table (Appendix 10).

2.4.1.3 *Searching for connections across emergent themes*

Once emergent themes had been chronologically listed for each case, efforts were made to establish connections between them by organising them into clusters of related themes. Clusters were given a descriptive label to indicate the conceptual nature of the themes within them, creating superordinate themes. Throughout this process, I attempted to check my own sense-making against that which was said in each of the transcripts (Smith, 2008). Finally, a table was produced outlining the superordinate and subordinate themes, along with complementary verbatim text excerpts to ensure that these labels were fully representative of the source material from participants (Appendix 11). This process was repeated for each case, taking particular care to bracket ideas that

¹⁰ focusing on what was said and the subject of talk within the text

¹¹ exploring the specific use language

¹² focusing on engaging with the texts at a more conceptual and interrogative level

had emerged from the analysis of previous transcripts. This helped ensure that new issues, as well as commonalities between themes could be identified (Smith & Osborn, 2008).

2.4.1.4 *Final list of master themes*

Once all seven interviews had been analysed, connections between the superordinate themes and theme clusters in each participant's summary table were clustered together to create a master table of superordinate and subordinate themes for all participants (Appendix, 12). Deciding which themes should be included necessitated prioritising the data and reducing the initial list. Themes were chosen by taking into consideration whether they appeared to be well-represented within the text, captured issues deemed to be of significance to the participants themselves, the depth and complexity of supporting excerpts, and relevance to the research questions (Willig, 2001; Smith, 2008). A record of decisions relating to the keeping and discarding of themes was kept as part of a reflexive diary (Appendix 13).

2.5 Quality in qualitative research

The constituents of 'good' qualitative research vary across authors (e.g. Elliot et al., 1999; Spencer et al., 2003; Yardley, 2008; Smith, 2011). However, fundamental elements appear to remain consistent. To ensure its quality and rigour, the following principles set out by Yardley (2008) were used to guide this study:

- Sensitivity to context
- Commitment and rigour
- Transparency and coherence; and
- Impact and importance.

A detailed discussion of each is provided in Chapter 4 (section 4.5).

2.6 Self-reflexivity

I am a 27 year old white female who grew up in a middle class family in Malta (Europe). I attended an all-girls Catholic primary and secondary school in Malta, where the schooling system is based on the British model. Consequently, I experienced a similar transition at the same time at which participants did. I moved to the UK in 2007 where I have since worked for the NHS, predominantly in psychology and child related settings. My theoretical position has been shaped by my training in clinical psychology, a programme largely informed by a social constructionist philosophy, along with my experiences of working within the NHS. Whilst my understanding of chronic illness is informed somewhat by the biopsychosocial model¹³ of health and illness, it is also informed by my own personal experiences of living with IBD as an adult, for the last four years (Crohn's disease). Overall, I would describe my approach to talking about my IBD as an 'open' approach. By this I mean that when asked, or when I feel it would be appropriate or helpful to do so (for the other person or myself) I choose to share detailed information about IBD, its symptoms and impact. My own experiences of talking about IBD within educational and professional settings have been mixed.

As far as was possible, I strove to commence interviews with an open mind and the intention of capturing these young peoples' own lived experiences. However, it is important to acknowledge that the questions asked, along with my non-verbal communication may have influenced the responses given and that a different researcher may have obtained somewhat different answers. Consistent with IPA, it is crucial to note that the assumptions and beliefs that I hold may have also affected how I understood and interpreted the data. With the intention of keeping my presuppositions in check, along with a desire to remain mindful of my pre-understandings, I maintained a reflexive journal during the course of the research (Appendix 13). It is worth noting that I did not share my diagnosis with any of the participants. Reasons for this, along with the impact I as a researcher may have had on the research process are discussed in further detail in Chapter 4 (section 4.4).

¹³ The biopsychosocial model supports the view that biological, psychological and social influences interact and shape people's functioning in the context of illness.

CHAPTER THREE: RESULTS

3.1 Participants

The background of each participant is presented in Table 1 (p.35). Whilst a description is provided in the section that follows, an overview of the course of their illnesses and experiences of disclosing IBD may be found in appendix 14. No specific questions were asked about these topics. This information was mentioned by participants within the context of their experiences. Consequently, this material has not been verified by anyone else.

Up until the time of the interviews, four participants described themselves as being in remission in secondary school (Danny, Dean, Sunaya and Will), stating that they had not experienced any significant flare-ups^{14, 15} of the illness and had not required inpatient treatment for their IBD in secondary school. One of these participants (Will) was receiving fortnightly injections of Adalimumab¹⁶ at the hospital where the research was conducted, and had previously been on a medical liquid-only diet. Three participants (Ella, Holly and Tyler) described themselves as having experienced relapses of their IBD in secondary school, stating that these flare-ups of the illness had been moderate in nature. Two of these participants (Holly and Tyler) required treatment as inpatients for these flare-ups. The other participant (Ella) required treatment as an outpatient, in the form of a once weekly course of eight iron infusions. Five participants (Danny, Ella, Holly, Tyler and Will) described themselves as having disclosed their diagnosis to at least two or three people (peers or teachers). The remaining two participants (Dean and Sunaya) described themselves as not having disclosed their diagnosis directly themselves to anyone in secondary school. Both of these participants stated that disclosure had been completely mediated by their mothers. In their cases, only teachers had been informed of their diagnosis. Consequently, whilst present, their voices are less prominent in the discussion of the themes below.

¹⁴ For the purpose of this study, non-significant flare-ups were considered to require the participant needing to open their bowels up to once a day.

¹⁵ 'Flare ups': term used to describe periods of active disease

¹⁶ Used to treat ulcerative colitis when other drugs have not worked or have caused major side effects

Table 1. Background of participants

Pseudonyms used for Participants	Gender	Ethnicity	Diagnosis	Age at interview	Age at diagnosis
Will	Male	Black British	Crohn's disease	12 years	9 years
Tyler	Male	White British	Ulcerative colitis	13years	7 years
Holly	Female	White British	Crohn's disease	13years	6 years
Sunaya	Female	British Asian	Crohn's disease	12years	4 years
Danny	Male	White British	Ulcerative colitis	12 years	8 years
Dean	Male	White British	Ulcerative colitis	13years	9 years
Ella	Female	White British	Ulcerative colitis	12 years	9 years

3.2 Themes emerging from the transcripts

This section presents the results of the interpretative phenomenological analysis of the seven participants' accounts of talking about an IBD diagnosis, a year after having transitioned from primary to secondary school. This analysis generated three master themes:

- 1) Managing a stigmatised identity
- 2) Relationship to identity and IBD
- 3) Disclosure as a double edged sword

These themes are presented in Table 2 (p.36), with the number of participants who identified each master theme and sub-theme in brackets. Quotes from participants will be used to support and explain each theme. Following each quote a coding in brackets has been included indicating the particular page and line number, so that each quote may be tracked back to its original transcript. As highlighted in chapter 2 (sections 2.2. and 2.4), within IPA the process of uncovering such themes is based on the double hermeneutic, whereby the researcher is making sense of a participant who is trying to make sense of their own lived experience, through a process of interpretative activity (Smith & Osborn, 2008). Consequently, these themes outline one possible account of how

young people experience talking about an IBD diagnosis following their transition to secondary school.

Minor changes have been made to the text extracts. To ensure confidentiality, all names and identifying information has been either removed or altered.

Modifications to text excerpts have also been made for ease of reading. Where words are implied but not stated, these have been placed in square brackets []. Where material has been omitted, the following brackets are used [...]. Examples of how these types of modifications were made may be found in appendix 15.

Table 2. Themes emerging from the interviews

Themes (number of respondents)	Sub-themes (number of respondents)
Managing a stigmatised identity (8)	Fear of negative peer behaviour (7)
	Fear of disease burden (3)
	The safety net of teacher and parental support (7)
	Balancing peer curiosity with stigma limitation (6)
Relationship to identity and IBD (8)	Dissociation (4)
	Tension between IBD and 'normality' (6)
	Beginning to come to terms with IBD (5)
	Acceptance (4)
Disclosure as a double-edged sword (8)	Emotional support (5)
	'Coming out of the closet' of invisible illness (5)
	Losing tight hold on information (5)
	Disabling attitudes and reactions (2)
	Surrendering privacy (4)

THEME 1

3.2.1 Managing a stigmatised identity

This was an important theme for all participants. It emerged from participants' reports of varying degrees of disclosure, ranging from not talking about their IBD at all, to limiting the amount which they said. Participants discussed this within the context of their concerns that disclosure (full or partial) could lead to them being rejected by peers at school. Concerns discussed for not disclosing the diagnosis included leakage of information, IBD related teasing, repelling and disgusting others, and burdening others with talk of their diagnosis. Participants also spoke about partially disclosing their diagnosis within the context of avoiding situations they deemed to be more socially threatening, including talking to avoid the embarrassment of soiling themselves at school, and disclosing just enough information to simultaneously satisfy peer curiosity and protect themselves from potential rejection. The following sub-themes highlight this further.

3.2.1.1 *Fear of negative peer behaviour*

All participants discussed not disclosing their IBD for fear that they would experience some form of rejection from their peers. Three participants (Will, Holly and Dean) spoke of their concerns that talking about IBD would leave them vulnerable to being rejected, teased or bullied because of their IBD. One participant emphasised this point by catastrophising this potential experience:

*"If people did tell other people, they might come to my school to bully me about the symptoms that I had, like the diarrhoea. That's my worst fear."
(Will 496-499)*

These participants spoke of a complex information management strategy, which was guided by their fears that telling less trusted people might result in the leaking of information to others who might use the information to bully or tease them. For example, one participant said:

"I wanted to keep it a secret so that no one else knows, except my best friends whom I trust. Because, if [other peers] told other people who I don't really trust, they might turn everyone in the school." (Tyler, 325-329)

Similarly, another participant (Dean) spoke of his concerns in relation to the leakage of information and potential teasing when talking to his teacher about his IBD:

"I didn't want them [peers] to hear [...] because some stupid stuff might happen [...] like making nasty remarks about it." (Dean 313-314)

Only one participant (Holly) spoke about fears of disclosing an IBD diagnosis in relation to past experiences of IBD-related teasing. She spoke, in particular, of feeling vulnerable and unable to withstand teasing related specifically to the symptom of diarrhoea:

"They [peers] would say things like, "You're a bit like a cripple really, aren't you?" and [...] then, they would start talking about bowel movements. I could take all of the other things but, for some reason, them [sic] making comments associated with bowel movements, that really upsets me. That's too much for me to deal with." (Holly 638-651)

Along similar lines, several participants spoke of their worries that talking about their IBD diagnosis and its symptoms, would disgust and repel people from them:

"If I talked about it, maybe some people would just act cool about it and remain calm. And some people would be in between, like, they wouldn't know what to do, wondering if they should stay away from me or something like that." (Ella 529-533)

The notion of IBD talk repelling people appears to be internalised by one participant (Sunaya), who spoke of being specifically advised by her mother against engaging in toilet-related talk at school:

“I never told anyone about that [going to the toilet] before, because when I was in primary school, mummy said it wasn't something to talk to people about.” (Sunaya 266-269)

3.2.1.2 *Fear of disease burden*

Three participants (Holly, Ella and Will) discussed not wanting to burden people, with ‘unpleasant’ details or more general talk about illness. One participant (Holly) spoke in particular of her desire to protect peers from disgusting and inappropriate information, particularly given the discrepancy between her own health and that of her peers:

“They can be such disgusting aspects, having diarrhoea and the other things, I just think, do people really want to hear about that, about someone else? They are healthy, [...] so why would they want to hear that about someone else?” (Holly 296-302)

Two participants (Holly and Ella) shared concerns that talk of their IBD would consume the fun of others or lead to being labelled a killjoy:

“During the Year 7 disco, I wasn't very well then, but I didn't really want to mention it to any of my friends at that time, because we were having fun and everything.” (Ella 325-329)

“I sometimes think maybe it might get too depressing or too boring for them and I don't want them to see me now, as oh I've been diagnosed with an illness so now I can't have fun, now it's all I talk about.” (Holly, 882-887)

3.2.1.3 *The safety net of teacher and parental support*

All participants discussed disclosing their IBD to teachers for practical reasons. They spoke of talking to teachers as enabling them to protect themselves from the embarrassment of soiling themselves whilst at school. Two participants (Will and Tyler) said they had disclosed their condition to teachers themselves, whilst the other five participants (Ella, Holly, Dean, Sunaya and Danny) defended themselves against this threat by having their parents disclose on their behalf:

“If I hadn’t given them [teachers] enough information, they wouldn’t know that I had diarrhoea. If they hadn’t already sussed it out, and if I needed to go to the toilet and they said no, then that would have been a problem.”
(Will 692-697)

“My parents went in for a little meeting thing [sic], just to say everything. [...] I thought it would be easier having every one of my teachers knowing, because if I did need the toilet they would know that I would have to go and I can’t hold it. Especially, when I actually am ill and I have to go like most times during the day.” (Ella 650-655)

The five participants (Ella, Holly, Dean, Sunaya and Danny) whose parents disclosed on their behalf spoke of their parent’s assistance as being supportive. Interestingly, most participants noted that parental support with disclosure at school bridged a gap that they needed to cross, but felt too psychologically immature to do so alone:

“At the time, I was too young and it was still quite new to me to tell them [teachers] on my own. My mum said things that I couldn’t bring myself to say. [...] In the beginning, I couldn’t tell people that I suffer from diarrhoea. It took me a while to tell them [teachers] that. After she spoke to them I could just go to the toilet when I needed to without any hassles or delays.” (Holly 1064-1077)

3.2.1.4 *Balancing peer curiosity with stigma limitation*

Participants also spoke of strategically revealing what they perceived to be less stigmatising information to peers. Participants spoke of the curiosity of peers in relation to school absences, treatments and symptoms as threatening their social identities. Five participants (Ella, Danny, Holly, Sunaya, Tyler and Will) acknowledged the need to disclose information to satisfy peer curiosity, but discussed balanced this with the need to protect themselves from potential rejection by limiting or obscuring the information they gave to peers:

"[...] There is a group of girls [...] I talk to them, but I don't talk to them about my personal problems. So, I can't really trust that what I told them would stay between me and them, that they wouldn't take [what I say] and use it against me. So I tell them just enough to satisfy them really. Like, I say it has something to do with my stomach, it causes pain and that it makes me feel sick and that's it. I then say, "If there's anything else you want to ask me, you can do", then I change the subject." (Holly 854-861)

Two participants (Tyler and Ella) discussed disclosing only treatment related information to particular peers, such as having injections and attending hospital appointments. Such information was considered to be the norm for other adolescents their age and, therefore, was safe to share:

"[...] Everyone can have an injection and stuff like that, but because the colitis is a part of me, erm, because it's just telling someone about [...] a part of you [...], it's easier telling people like what I have to have done." (Tyler 709-718)

One participant (Tyler) differed from the four participants who engaged in limited disclosure (Ella, Danny, Holly, Sunaya and Will). This participant spoke of openly disclosing his diagnosis to close friends, describing it in great detail to them. He medicalised his increased toilet use in the hope that this would normalise the experience and protect himself from being teased:

"I told them [close friends] what was actually proper [sic] wrong, so they don't think it's something else. [...] I don't know, like I'd eaten something dodgy or something like that and take the mickey." (Tyler, 231-234; 238-239)

THEME 2

3.2.2 Relationship to identity and IBD

All participants discussed disclosure of IBD within the context of their own developing identity. Participants spoke of disclosure as being contingent upon the degree to which they had accepted the diagnosis of IBD itself. Participants'

discussed experiences of disclosure and non-disclosure which oscillated between three differing levels of acceptance. The following sub-themes will highlight this further.

3.2.2.1 *Dissociation*

Several participants spoke of non-disclosure as helping them to distance themselves from their condition. Four participants (Dean, Ella, Will and Sunaya) denied the permanency of their condition and consequently felt no need to disclose their IBD diagnosis. These participants spoke of IBD as being a temporary state. Feeling that 'normality' would soon ensue, they did not perceive IBD to be part of their identities, and consequently chose not to talk about it:

"Because I knew they [iron infusions] were nearly done, I was just like, there's no point in telling anyone else, because they're almost done." (Ella 126-130)

"I can't be bothered to tell people at school. I want to be the same as everybody else, I am the same. Plus, it was a long time ago and I don't really care anymore." (Dean 455-458)

This denial of the chronicity of IBD was most apparent in the two participants who described themselves as not having experienced any significant flare-ups in secondary school (Dean and Sunaya). These two participants experienced a sense of dissociation between themselves and the diagnosis of IBD:

Researcher: "What's that been like for you, not telling people that you have colitis?"

"Well, I forget about it when I'm at school." (Sunaya 99-102)

"What have I got again [question asked to researcher]? I keep forgetting it. It's a weird name."

Researcher: "I think you said it was colitis at the beginning of the interview."

"Oh yeah! Colitis." (Dean 605-609)

Interestingly, whilst no questions were specifically asked, during the interviews several participants spoke of the time leading up to their diagnosis or the period shortly ensuing it. Two participants (Dean and Ella) specifically referred to this period of time in relation to experiences of not disclosing to peers. Both participants spoke of their strong desire to avoid disclosure to prevent having to re-live a traumatic time in their lives:

“It was fine talking to teachers. Apart from, I really wasn't listening to what I had, so I wasn't sure what to respond. I wasn't really listening to what the doctors were saying half of the time. It was very scary when I was diagnosed. I'd been sick for eight weeks and had lost a lot of weight. No one knew what it was until we came here [hospital where research took place]. I hated being in here, I hated everything about it. So, I really didn't want to talk about it to anyone else.” (Dean 350-360)

3.2.2.2 Tension between IBD and ‘normality’

Six participants (Ella, Holly, Danny, Sunaya, Will and Dean) discussed experiencing a tension between disclosing their IBD diagnosis and retaining, what they perceived to be, their ‘normal’ identities. One participant (Will) reflected upon this predicament by externalising and distancing himself from the label of disability by comparing himself to those with more visible disabilities:

“I mean, there's no real need for me to talk. I'm not the same as them (peers), obviously. But, I am. I don't, [...] feel any different [...], I don't walk in a different way, I don't speak in a different way. Not disabled people are like anyone else, they're just unfortunate.” (Will 519-520)

Four participants (Ella, Holly, Danny and Dean) spoke of concerns that disclosure might affect their sense of normality. These participants strove to maintain a sense of normality in their school lives by disclosing a limited amount of information:

“I tell them something different all the time. I don't tell them the truth, I just say I was sick with something or I went to the doctor's. [...] I just answer

their questions so that stuff goes back to normal and we're all fine about it, and we just do what we normally do, going around the school and stuff."
(Dean 178-181)

"He [peer] just came to me and asked why I was off school and I just said that I was sick and I went to the doctors, or something, and had a blood test. And then stuff went back to normal. He treated me like everyone else." (Danny 240-247)

One participant (Holly) commented on her concerns that talking about her IBD would consume her preferred social identity at school, that of a 'normal' young person, and would attract an unwanted and undesirable identity in its place. She spoke of wanting her identity to remain separate from her illness:

"I just don't want to be 'Holly with Crohn's', I just want to be 'Holly', I don't want things to really change, where my friends think [...] that all I like to talk about is my illness, because that's all I can talk about. That's not what I want them to think." (Holly 894-900)

On a similar note, three participants (Holly, Ella and Will) shared concerns that talking about their diagnosis with peers or teachers would result in 'special treatment'¹⁷ at school. They felt this would be, or had been, a major threat to their desired identities at school, that of a 'normal' adolescent:

"In the beginning I actually thought, [...] well at least they [peers] care. They realise that I'm capable of knowing when I'm not feeling well and they will stop asking. But they didn't. And it just made me feel like a little child."
(Holly 361-366)

"I didn't tell them [teachers in secondary school] because I didn't want the teachers to treat me differently. I want to be the same." (Will 123-125)

¹⁷ When people are treated in preferential ways or adaptations are put in place, in this case, to take into account their diagnosis of a chronic illness

These three participants (Holly, Ella and Will) also shared concerns of being pitied or overprotected by their peers, viewing these as being particularly threatening to their identity as a 'normal' young person at school:

"Sometimes I don't want people to know I've got an illness. I don't want people to start the whole pity party, you know, 'Oh, you poor thing! I feel really sorry for you'". (Holly 677-681)

"I was worried that they [close friends] might have panicked after I told them, like saying, 'Are you all right?' constantly, and just, like, being a bit too nice to me. Like, if it was at school they would probably take my bag off me and carry it. They'd be too nice to me." (Ella 436-441)

3.2.2.3 Beginning to come to terms with IBD

Five participants (Danny, Ella, Holly, Tyler and Will) commented on the changes they noticed in the ways they talked about their IBD, particularly following their transition from primary to secondary school. They spoke of their increased ability to talk about their IBD in secondary, and associated this to their feeling more confident and familiar with the condition:

"When I got diagnosed I was in primary school, and I would have been shy about talking about it and I wouldn't really know what to tell people. [...] In primary [sic], my confidence [...] was small and it was kind of weak, like an ant. In secondary school it's been more like a tiger. [...] Because, tigers are strong and they are bigger than an ant and they have more power." (Ella 555-564)

Two participants (Danny and Holly) in particular, explained how beginning to embrace IBD as part of their identities in secondary school allowed each of them to talk more about it:

"It [IBD diagnosis] was quite new to me and it's taken me a long time to fully understand it myself. I was, kind of, still getting to grips with it in

primary. It was harder to know what to tell them [peers] in primary school.”
(Danny 1014-1024)

“I think now [in secondary school] I am a lot more open with people, I tell people a lot more about my illness than I ever did in primary school. And I think that's because I've accepted my illness a lot more myself.” (Holly 1170-1174)

3.2.2.4 Acceptance

Four participants (Holly, Ella, Tyler and Will) commented on disclosure of IBD as being a way in which their true identities had come, or could come to be known, by their peers at school. Two participants (Ella and Tyler) spoke positively about this process of true self-revelation through disclosure to their close friends:

“I didn't tell her [best friend] anything else after that, because that was it, what I'd told her. There was nothing else to tell. [...] I told her about my illness and what happened and everything, so I told her the whole story really and, [...] so, there was nothing left to tell. I told her the story from the beginning, so she knew everything about me and it felt good.” (Ella 403-413)

Three participants (Holly, Tyler and Will), two of which (Holly and Will) expressed concerns about being identified with their illnesses in section 3.2.2.2, seemed to have accepted and internalised their IBD diagnosis, using phrases such as, “*My illness*” (Holly 259) repeatedly throughout the interviews. One participant (Holly) stressed the importance of disclosing her IBD diagnosis to peers, so that they could come to accept her diagnosis, just as she had:

“Before I told them [close friends], I thought, if I tell them about it [IBD diagnosis] and they are not liking what they're hearing, then that's their problem, because it's a huge part of my life. So, for us to be friends, you're going to have to accept it, and you're going to have to know about my illness.” (Holly 252-259)

THEME 3

3.2.3 Disclosure as a double-edged sword

This theme emerged through a discussion of young people's experiences of what helped and hindered talking about their IBD. All participants spoke of experiencing various psychological benefits and consequences, in relation to the disclosure or non-disclosure of their IBD diagnoses to people in secondary school. Participants discussed psychological benefits of self-disclosure ranging from feeling less isolated to feeling liberated and contained. Psychological costs experienced by participants in talking about IBD, included powerlessness over the control of IBD related information, experiencing disabling attitudes from others, and the surrendering of their privacy. In discussing their experiences of these psychological costs and benefits, some participants spoke of a reciprocal relationship between attaining some degree of acceptance or 'ownership' of IBD and the process of disclosure. Therefore, whilst acceptance of IBD appeared to facilitate disclosure, disclosure also seemed to facilitate an acceptance of the illness by encouraging these young people to 'own' their IBD more publicly. The following sub-themes highlight the issues raised.

3.2.3.1 *Emotional support*

Five participants (Danny, Ella, Holly, Tyler and Will) mentioned disclosing to others within the context of feeling less isolated. Four participants (Danny, Ella, Holly and Tyler) spoke of feeling less isolated in relation to feeling cared for and supported after having talked to peers and teachers about their IBD:

"[When] I came back from being sick, everyone else was like normal, saying, 'Tyler why were you in hospital?', But the three that I told were [...] making sure I was actually okay, okay. [...] Everyone else went straight out to break and played [...]. But they all bought me drinks and stuff, [...] to make sure I'm [...] all right, so I'm not flared-up as much." (Tyler 368-381)

"They [teachers] were just there for me to speak to if I needed to speak to anyone. They asked how I was feeling and stuff like that. It made me feel better just telling someone about what I was feeling and [...] them just

listening and being supportive. It was nice for them to there for me.”
(Danny 221-229)

Interestingly, four participants (Ella, Danny, Tyler and Will) spoke of their comfort in talking to peers or members of staff at school (teachers, dinner lady) who had the same or similar diagnoses to them. Talking about their shared experiences at school reduced loneliness and contributed to a sense of belonging:

“It’s nice that I know someone who knows what it’s like to deal with Crohn’s or colitis. Because, obviously, his wife [PE Teacher] has it, and she’s mostly tired and everything. So, he gets what I’m saying and everything.” (Ella 707-712)

This was further supported by one participant (Tyler) in particular who, in addition to an increased sense of community, described such talk as potentially offering him and his peers with IBD the opportunity to create a new sense of ‘normality’ at school:

“I thought I was going to be the only one in the entire school, it turns out that I weren’t. So, if loads of people know about one person has it, it will be okay if lots of people know that two people have it, so it will be quite a regular thing that a few people have.” (Tyler 597-602)

The importance of not feeling alone with the experience of IBD at school was further bolstered by two participants (Will and Dean) who spoke of concerns that non-disclosure would result in their isolating themselves from their peers:

“When they [peers] ask me [why he’s been off school], I swear at them, and then they just go, “Yeah, fine” and walk away. But I don’t swear all the time, because I don’t want them to go away.” (Dean 194-198)

3.2.3.2 *Coming out of the closet of invisible illness*

Five participants (Danny, Ella, Holly, Tyler and Will) described disclosing to people at school as freeing them from the psychological stress of concealing their IBD diagnosis. They spoke of feeling a sense of liberation after telling peers about their IBD diagnosis:

“I just felt happy, because I just wanted tell someone and get it out of my system, because I was, like, keeping it inside. Then I told Kate [peer], and I just felt happier after I told her.” (Ella 153-160)

In addition to feeling liberated, two participants (Danny and Will) spoke of feeling contained and safe when talking to peers about their IBD:

“It [talking to friends] feels good because [...] I know that they would listen to me and I know I can speak to someone about it and they won't go telling other people that I don't want to know.” (Danny 484-487)

The significance of feeling liberated through the act of disclosure was further supported by two participants (Holly and Will), who spoke of their not having disclosed as weighing heavily on their sense of morality. Two participants spoke of feelings of guilt (Holly) and deceit (Will) in relation to not having talked about their IBD, a significant aspect of their identities:

“I regret now not telling them as much as I should have. I should have told them the whole truth. I should have said it and then if they didn't like it or accept it, then that would have been it.” (Holly 1020-1024)

“Some people might come up to me after class and go, ‘Oh Will, why are you allowed to go to the toilet?’, and then I'd have to tell them. Well, I wouldn't have to tell them, but I'd feel like, I was lying to them.” (Will 130-134)

3.2.3.3 *Losing tight hold on information*

Two participants (Danny and Ella), in discussing their experiences, repeatedly spoke of their apprehension in talking to more people (both teachers and peers) about their IBD. Both participants used the phrase, *“Mixed feelings”* (Ella 466) throughout the interviews when talking about past and potential disclosure experiences. One participant (Danny) in particular, elaborated on this, describing his sense of regret after having disclosed his IBD diagnosis to one of his teacher in primary school:

“I have mixed feelings and mixed thoughts about it [disclosing IBD to teachers in secondary], because I don’t know how they [teachers] would react. When I told some of my teachers at the end of primary school, [...] after, I thought, ‘I shouldn’t have done this’.” (Danny 171-178)

Five participants (Danny, Ella, Sunaya, Tyler and Will) discussed their concerns that their self-disclosure would result in news of their IBD diagnosis being spread by others in the school. Four participants (Danny, Ella, Tyler and Will) discussed this experience having already disclosed to others (peers and teachers) themselves. Having disclosed, these participants spoke of feeling powerless to control the amount known about them and their illness by others. They spoke of their concerns that their lack of control over disclosure would leave them exposed and unprotected from negative peers interactions, such as bullying and teasing:

“[...] I thought them three [close friends he had disclosed to] had told everyone. [...] I thought I was going to be taken the Mickey out of in front of everyone but I wasn’t. When we went to break I asked them, ‘Why was everyone happy?’ and, they just said, ‘Because you were in hospital and you came out’.” (Tyler 411-416; 434-438)

“I felt scared about the way they [teachers] would react. And if they [teachers] would go around telling everyone, and then I would get bullied by people, because of my friends then telling everyone.” (Danny 186-188)

One participant (Sunaya), whose mother disclosed to teachers on her behalf in secondary school, spoke similarly of concerns over her powerlessness to prevent her IBD-related information from being spread to others at school:

“Sometimes I feel a bit in the middle, like happy, kind of. Because, if she [mum] tells somebody that I don't know, then I don't know them. So, they could tell somebody that she doesn't trust.” (Sunaya 448-466)

3.2.3.4 Disabling attitudes and reactions

Two participants (Will and Holly) spoke of their disappointment at the reactions they received from others (peers and teachers) after revealing, what they felt to be, a big part of their identity. They spoke of feeling angry and frustrated at those who remained ignorant, even after having talked about the condition:

“When I was on my liquid diet, I was only allowed Sprite¹⁸. My friends [who he had disclosed to] would always come up to me saying, ‘Can you give me a can of Sprite?’ It was annoying, because I thought to myself, I want to drink my Sprite. None of you can have it. It's mine. I felt like it [Sprite] was part of me, because I just drank Sprite and elemental¹⁹ so much. They never asked for the elemental. They just wanted my Sprite.” (Will 460-472)

“This teacher said that she knew someone who had irritable bowel syndrome and that it wasn't that bad. When I tried to explain to her that it was different, she wasn't having any of it. She knew best. And I sat there and thought, ‘I've wasted my time telling you.’” (Holly 89-94)

One participant (Holly) elaborated on this, describing her struggles in challenging her teachers' inaccurate understandings of her less visible health condition. Having spoken to her teachers on numerous occasions about her IBD, she spoke of feeling betrayed by their disabling attitudes. In particular, she spoke of how

¹⁸ Soft drink

¹⁹ Also known as a 'bowel rest' diet - liquid diet which contains the body's basic nutrients.

teachers had made her feel like a 'drama queen' and a manipulative young person:

"My old form tutor [...] knew about my illness, but he would say things like, 'You sure know how to milk it', and 'You're looking fine to me', and I said, 'Yes, that's because I'm on steroids because my illness is so bad, and I'm not long out of hospital'. And he was like, 'But I don't understand, because you look so good', and I said, 'It's in the inside. You can hide pain and what's inside very well'. So, you don't understand and you're my form tutor, you should be able to understand that [...]. You should be here for me to talk to or if I need some support." (Holly 699-722)

3.2.3.5 Surrendering privacy

Four participants (Dean, Holly, Tyler and Will) spoke of disclosing their IBD to others (peers and teachers) as infringing upon their privacy. All discussed experiencing intense reactions in relation to actual or potential losses of privacy, including anger (Dean and Holly) and mortification (Holly and Will). The intensity of these emotions are captured in the following quotes from one young person (Holly) who had disclosed to her peers and teachers, and another (Dean) who had not disclosed to any of his peers:

"He [teacher] came in the next day and said I googled²⁰ your illness. It felt horrible! I felt like my privacy had been invaded. I just felt, 'Why did you do that? You should have asked me and I would have told you as much as I wanted to tell you. Now you know way too much.'" (Holly 589-593)

"They [peers] just don't need to know, and I really don't need to tell them. It's none of their business. When people at school have asked questions I just told them to, 'P-I-S-S off'". (Dean 500-501)

Two participants (Holly and Tyler), spoke of a sense of helplessness and hopelessness in maintaining a degree of privacy from others at school once their

²⁰ To search for information about (someone or something) on the Internet using the search engine Google

condition became more visible and harder to conceal (e.g. due to visibility of symptoms, treatment, hospital appointments). In these instances, these participants spoke of feeling pressed to disclose and surrender their privacy as the visibility of IBD increased:

“When I started bleeding [from anus] and I got admitted to hospital, it became obvious that there was no way around it. They would clearly know that something was wrong, and I couldn't keep that from them anymore. [...] In a way I thought, this is it, I'm going to have no privacy now because anyone who is part of my life, I have to tell, I haven't got a choice really.”
(Holly 390-401)

One participant (Will), who had been in remission during secondary school, spoke of the increased invisibility of his IBD as freeing him from the pressure of having to talk about it at school:

“I talk about it less now, because in primary school, I couldn't really hide it, because I couldn't eat. I didn't really eat, I just drank. I just drank and ate Harribos [sweets].” (Will 338-342)

CHAPTER FOUR: DISCUSSION

4.1 Overview

This chapter will first outline the main findings of the study in relation to the research questions, existing theory and literature. As IPA, along with other qualitative approaches, habitually lead to the discovery of new and unexpected themes during the interview and analysis stages, some of the literature introduced below is new (Smith et al., 2009). Following this, the psychological implications of the finding are presented, along with service and clinical implications. A discussion of methodological issues arising will follow this. Finally, ideas for future research will be presented.

4.2 Discussion of findings

The following section discusses the main findings of this study in relation to the three main research questions, which were:

- 1) How do young people with IBD manage the disclosure of their condition?
- 2) How are young people's experience of disclosing and talking about IBD affected by their transition from primary to secondary school?
- 3) What facilitates and hinders talking about IBD as a young person living with this condition?

Findings will be discussed in relation to the themes which most consistently addressed the above research questions.

4.2.1 How do young people with IBD manage the disclosure of their condition?

One consistent theme emerged from the participants' transcripts that addresses the above research question.

4.2.1.1 *Managing a stigmatised identity*

In discussing their experiences participants spoke of three disclosure management strategies. Firstly, not talking about their IBD to manage leakage of information and keep their 'invisible' and stigmatisable condition concealed. Secondly, disclosing, but only revealing what they perceived to be less

stigmatising information. Thirdly, disclosing IBD information only to teachers to ensure practical needs (namely the need to go to the toilet regularly) were met. These strategies were utilised interchangeably at school by all participants. Similar to the participants in Dyson et al.'s (2010) study, participants in this study commented on the use of such disclosure strategies within the context of wanting to protect themselves from acts of peer rejection; namely perceived, potential or actual teasing and bullying from peers.

These disclosure strategies appeared to fit with two stigma management strategies defined by Goffman (1968). In choosing not to disclose their IBD, participants appeared to be utilising the stigma management strategy termed 'passing' (Goffman, 1968), deliberately concealing their IBD by not talking about it. Participants also appeared to engage in the stigma management strategy 'covering' (Goffman, 1968), by limiting the potentially stigmatising aspects of their condition through partial disclosure. Using disclosure in these ways suggests that these young people considered their IBD to be a potentially 'discreditable' aspect of themselves, and that disclosing to others at school, particularly peers, would risk them being rejected and stigmatised. This appears to be in line with wider literature, which notes the link between 'invisible' illnesses and stigma in adults (Gray et al., 2000; Van Brakel, 2006; Weiss et al., 2006). The findings of this study would, therefore, suggest that IBD is experienced by these young people as a potentially stigmatisable identity.

Most young people in this study appeared not to disclose because of concerns relating to the potential stigma attached to IBD and its symptoms. The stigma believed to be attached to toilet-related talk and, in particular, diarrhoea seemed to be a significant threat to the social identities of these young people. Several participants spoke of not disclosing for fear that such talk would disgust people and repel them. This appears to support the suggestion of Donoghue and Siegel (1992) and Diener (2011) who note that social discourses around people not wanting to hear talk of such symptoms influences people in thinking that certain types of illness should not be talked about. These young people's fears of IBD related-talk repelling people also appears to support existing research (e.g. Gray et al., 2000; Greene, 2009) that highlights increased disclosure of invisible

illnesses as correlating with the increased social acceptability of those conditions, and vice-versa. While participants' reluctance to talk may relate to more general societal discourses around the social unacceptability of illness related talk, these young people's particular fear of talk relating to bowel movements highlights a unique threat to social identity, one not described by previous research exploring other invisible illnesses. Similar to the way in which AIDS carries stigma by means of its association with perceptions surrounding homosexuality (Millen & Walker, 2000), an IBD diagnosis seemed to carry its own particular sense of stigma for the young people in this study, by way of its association with diarrhoea and faeces. The symptom of diarrhoea may be particularly stigmatising given its association with the notions of (un)cleanliness and contagion. The coarse humour that often accompanies diarrhoea related urgency may also serve to fuel such stigmatisation. Images circulated by popular culture and media could be a potential source of this, given that adolescents are considered to be mass consumers.

Participants' reluctance to talk about IBD and its 'undesirable symptoms' may also be associated with these young people's psychosocial stage of development (Erikson, 1968). Talking to another about faeces or bowel movements is an activity typically engaged in when people are at a very young age and are dependent on others for help in these areas (e.g. babies, toddlers, and pre-schoolers). Such talk tends to dissipate once children enter primary school. In the UK, the transition to secondary school overlaps with another significant developmental transition; the transition from child to adolescent. At this stage, talk relating to bowel movements would be considered to be out of the norm. Consequently, talking about a chronic condition that entails faeces-related talk may not only be deemed socially unacceptable, but may also be conceived by these young people to be a significant threat to their emerging social identities as adolescents inasmuch as it may be construed as a sign of dependence and immaturity. This hypothesis is in line with Erikson's (1968) account of adolescents as being increasingly concerned with the social impressions and judgements made of them by others, particularly their peers, during this developmental stage.

Similar to research with people living with cancer (Gray et al., 2000; Tam et al., 2003; Ashing-Giwa et al., 2004), three participants spoke of not talking to peers about their diagnosis to avoid burdening them with this information. However, in contrast to these studies, the burden described by these people seemed to be of a different nature. Whilst people living with cancer discussed not disclosing to prevent burdening people with information which might cause them to worry about them, these young people spoke of not burdening others with 'unpleasant' details and more general talk about illness. Participants who spoke about this burden simultaneously highlighted the differences between their lives and those of their peers, namely their diminished health.

Whilst people living with cancer are reported as doing this for dyadic reasons, the young people in this study seemed to be motivated by more personal reasons. This appears to be supported by the fact that participants chose to adopt a 'passing' rather than a 'covering' strategy, the latter of which is typically utilised to help 'normal' individuals (those without health conditions) to feel comfortable around the person with the health condition (Joachim & Acorn, 2000). One hypothesis is that, similar to mothers who chose not to disclose their HIV status to their children (Schrimshaw & Siegel, 2002), these young people may fear that their peers are too young and immature for illness related talk. In addition to the worry that the 'unpleasant' nature of IBD, because illness related talk is typically associated with the elderly (Stone, 2005), IBD related talk may be construed as a threat to the notion of adolescence, given the adult nature of this topic. This, together with peer immaturity, may put young people who chose to disclose their IBD at risk of being ejected from the adolescent world they have only just entered, by means of stigmatisation and peer rejection.

Several participants in this study spoke of revealing their IBD to teachers for practical reasons, namely, to prevent potentially soiling themselves whilst at school. For all the young people in this study, the threat of soiling themselves whilst at school appeared to be more socially dangerous than the act of disclosing IBD itself. As suggested above, given the socially assumed relationship between lack of bowel control and early childhood (and perhaps even old age), negative social assumptions about those who soil themselves may be

internalised by the young people and construed to be a threat to their emerging social identities as adolescents. Consequently, to protect against this threat, these participants disclosed their IBD and in doing so adopted a 'covering' rather than 'passing' stigma management strategy (Goffman, 1968). Therefore, disclosing IBD to their teachers minimised the harmful and stigmatising effects of IBD anticipated by these young people, more specifically, the threat of soling themselves in front of their peers at school.

As noted by Joachim and Acorn (2000), physical and behavioural differences (e.g. increased toilet trips, school absences and medical treatment) may make an individual stand out from others, consequently subjecting them to possible stigmatisation. To limit the perceived social threat that peer curiosity invited, the young people in this study engaged in preventative disclosure in a somewhat different manner to that described by Troster (1997). Whilst, as described by Troster (1997), participants divulged information relating to their IBD to limit socially threatening consequences of not doing so (e.g. the risk of drawing more attention to themselves and their 'invisible' difference) in these instances, participants only gave information they perceived to be less stigmatising (e.g. instance telling peers they had a stomach problem instead of a bowel related illness). Therefore, it seems that partially disclosing information enabled these participants to simultaneously protect themselves against two distinct threats to their social acceptance; not satisfying peer curiosity, and revealing information that could potentially socially discredit them in some way. Having to balance these two needs could be one reason why participants with chronic illnesses in the Lightfoot et al. (1999) study found managing peer curiosity at the beginning of the school year to be particularly challenging.

On the whole, participants talked about only disclosing information to peers about experiences which they considered to be normal for young people their age (e.g. talk relating to injections and doctor's appointments). Again, these participants seemed to feel that engaging in such talk protected them and limited the risk of stigmatisation. However, interestingly, one participant spoke of disclosing IBD fully to his peers to ensure that his peers understood that his increased toilet use at school related to a medical condition. Using talk to reinforce the medical nature

of his difference seemed to protect him from, what he perceived to be, a more stigmatising identity; the identity of one who goes to the toilet a lot for no medical reason. Although widely debated, this finding correlates with research carried out with people with mental health conditions which postulates medicalising mental health as reducing its associated stigma (Corrigan et al., 2002). Similar to such mental health related research, it is possible that this young person disclosed his IBD and specifically attributed his symptoms to a medical condition to absolve himself of the blame of his socially deviant actions, that is, for having the symptoms that he did (Conrad & Schneider, 1980).

Several participants spoke of the support they received from their parents in talking to others at school, in particular teachers, about their IBD. Interestingly, some of the young people in this study welcomed parental support and described parental disclosure to teachers as being particularly helpful as it protected them from soiling themselves whilst at school. This was an unexpected finding, as within western societies increased autonomy from parents is posited to be one of the key developmental tasks during this phase of adolescence (Erikson 1968; Havinghurst, 1953; Kroger, 2000). Parental involvement in aspects of adolescents' lives which ordinarily would be ignored is an observation commonly noted in the management of chronic paediatric condition, such as diabetes (Wysocki, 1993). Many of the young people in this study described parents who disclosed on their behalf as bridging a necessary gap that they alone felt psychologically underprepared to do. This appears to relate closely to the concept of scaffolding developed by Vygotsky (1978) where, by disclosing to others at school on their behalf, these young people felt enabled to go beyond their independent abilities and efforts. Therefore, this finding suggests that for these participants parental involvement, rather than being seen as conflicting with their developing sense of autonomy (Coupey & Cohen, 1984), was experienced as a compromise between wishing to appear independent and feeling unable to broach certain topics with teachers.

4.2.2 How are young people's experiences of disclosing and talking about IBD affected by their transition from primary to secondary school?

One consistent theme emerged from the participants' transcripts that addresses the above research question.

4.2.2.1 Relationship to identity and IBD

The period following the transition from primary to secondary school overlaps with a range of changes and transitions within the biological, psychological, and societal spheres (Kroger, 2000). During this period, many new events and changes are experienced at the same time, all of which raise important identity related considerations for young adolescents (Kroger, 2000). The central developmental task encountered by young people during adolescence is the defining of their identities (Erikson, 1968). All the young people in this study spoke of their experiences of disclosing IBD in secondary school within the context of their emerging identities. Charmaz (1983) notes that issues relating to identity and 'the self' are particularly heightened for people living with chronic illness, but are most notable at times when people view themselves and their lives as being fragile. For the young people in this study, negotiating new relations in secondary school within the context of living with a chronic illness may have constituted as such a period of increased vulnerability (Dyson et al., 2010).

All the young people in this study discussed their experiences of disclosure and non-disclosure within the context of three oscillating levels of self-acceptance. These experiences of disclosure and non-disclosure in secondary school appeared to relate closely to stages grief outlined by Kübler-Ross (1969), namely those of denial, bargaining and acceptance. Charmaz (1983) notes that people with chronic illnesses tend to demonstrate what she termed to be a 'loss of self'. Indeed, all the young people in this study, in discussing experiences of disclosure in secondary school, appeared to express a heightened self-concern in relation to the person they saw themselves becoming, and the self-images from the past which they felt they had lost (Charmaz, 1983). For them, disclosure and non-disclosure appeared to be used as a tool to help them to address the 'loss of self' that they experienced in secondary school.

Several participants discussed talking to people at school about their IBD as being a particular threat to their valued identity, namely that of a 'normal' young person rather than a 'sick' young person. This finding is consistent with existing literature on adults with invisible chronic illness (e.g. Admi, 1995; Gray et al., 2000) which suggest that non-disclosure relates to people's desires to live 'ordinary' lives or to have their lives revert back to 'normal'. Indeed, Charmaz (1983) notes that for people with chronic illnesses preserving a 'normal' life frequently comes to be the symbol of a valued self. However, for these young people, having just entered adolescence and a new school, the desire to retain a sense of normality their lives may be ever more significant. Therefore, these participants may have felt that not talking about their IBD enabled them to protect and maintain their valued 'normal' identities.

Narrative therapy approaches advocate that narratives or stories (personal, social and familial) all serve to shape an individual's identity (White & Epston, 1990). Erikson (1968) concurs, highlighting that during adolescence the development of identity is in part achieved through young people's interactions with their peers. Just as identity may be developed through interaction with others, Charmaz (1983) argues that the 'self' may just as easily be lost through social encounters. Three participants spoke of not disclosing their IBD at school to prevent the initiation of 'special treatment' from peers and teachers, such as overprotection and pity. If, following disclosure, actions such as pity and overprotection had taken place, this may have severed these young people's connection with their, "past pre-illness self" (Charmaz, 1983, p. 183), thereby contributing to a loss of self. Accordingly, these participants may have chosen not to talk about their illness, or to limit that which they said, to prevent losing their pre-IBD selves at a time in their lives when they were experiencing many other additional changes and challenges to their identities.

Four participants spoke of not needing to talk about IBD or aspects of the condition within the context of viewing these to be temporary rather than chronic affairs. Two of these participants, both of whom had not experienced a relapse of their IBD whilst in secondary school, discussed non-disclosure within the context

of forgetting that they had the condition. Therefore, it seemed that the young people in the study who experienced dissociation between themselves and the chronicity of their IBD diagnosis felt less of a need to talk about it. Not talking about IBD may relate to these participants' experiences of living with a less visible illness and its relapsing and remitting nature. Checton and Greene's (2012) study found symptom uncertainty in particular to be negatively associated with disclosure in older adults with heart conditions. Holding in mind that for many, the diagnosis of IBD itself may be relatively new, the young people who have been relatively well in secondary school may wonder whether it is worth abandoning their sense of normality at this seemingly important time of their lives by disclosing an illness which may not flare-up during their time at secondary school. Consequently, for some, not talking about IBD in secondary school might have been experienced as a 'fresh start'; an opportunity to explore and develop an identity outside of their illness.

Whilst non-disclosure at this stage of their lives might allow young people to discover an identity independent of their illness and parental figures, it may also, in part, result in an 'identity crisis' (Erikson, 1968); a time in their lives where they may lack a strong sense of who they are and where they belong. This was perhaps most apparent in participants discussions of their experiences of non-disclosure, where they described feeling as though they were living in-between two worlds (Moss & Dyck, 2002); the 'normal' world and the world of physical illness and disability. This finding appears consistent with Dyson et al. (2010) study which suggested that young people's uncertainty about disclosing their SCD at school related to their experiencing a tension between acknowledging the reality of living with SCD, and not wanting SCD to be a dominant part of their identities.

In describing their experiences of disclosure, three participants repeatedly used phrases such as, "My illness", suggesting that they had internalised their IBD diagnosis and that this now formed part of their identity and sense of self. These participants seemed to equate disclosure with the experience of being fully known by others at school. This suggests that these young people experienced disclosing their IBD to others to be a helpful tool in terms of their self-discovery

and development (Charmaz, 1983). Several participants also spoke of their increased ability to talk about their IBD in secondary within the context of feeling more confident and familiar with the condition. Whilst these changes might be best explained by increased levels of understanding and capacity for higher-order reasoning (Piaget, 1972), these young people having had a chance to adjust to their condition, may also feel they are in a better position psychologically to talk to others about it. Participants increased desires to talk about their IBD may reflect these young people learning that this condition does not have to diminish their self-identity and that indeed, as the narrative therapy approach maintains, a young person may live with an illness without it becoming their dominant 'story' or identity (White & Epsom, 1990).

Interestingly, several participants discussed their experiences of non-disclosure in relation to unpleasant experiences associated with the time of diagnosis or the period shortly ensuing it. Greenberg (2009) acknowledges that, for some people, illnesses may be experienced as traumatic events. Similar to people who have experienced traumatic events, two participants discussed their non-disclosure within the context of wanting to avoid reliving a time in their lives that they appeared to perceive as traumatic. This finding appears to be consistent with the findings of a study exploring the role of disclosure in coping with HIV, which suggests that adult participants experienced disclosing their HIV status to be an acute and recurrent stressor, with most choosing to adopt a policy of non-disclosure immediately post-diagnosis (Holt et al., 1998). The main reason cited in this study for such non-disclosure was that this allowed participants an opportunity to come to terms with their diagnosis prior to their having to deal with the reactions of others. Whilst psychological approaches to trauma-focused work tend to differ, most approaches agree upon the importance of creating a 'safe space' or position from which a person may contemplate and talk about the experience of trauma without experiencing this as being re-traumatising (Meiser-Stedman, 2002; White, 2005). For the young people in this study, simultaneously negotiating new school relations in secondary school, an adolescent identity and what it meant to live with a chronic illness may have been too much for them to simultaneously cope with psychologically. Consequently, these young people may not have felt that they were in a psychologically 'secure enough' position

within which to explore or discuss a traumatic aspect of their lives which they as yet may have still been coming to terms with.

4.2.3 What facilitates and hinders disclosing and talking about IBD as a young person living with this condition?

One consistent theme emerged from the participants' transcripts that addresses the above research question.

4.2.3.1 *Disclosure as a double edged sword*

All of the young people, in discussing their experiences, spoke of what helped and hindered talking about IBD at school. In addition to issues of potential stigmatisation and 'loss of self' (see sections 4.2.1.1 and 4.2.2.1 respectively for detailed discussion), all spoke of experiencing various other psychological benefits and consequences, in relation to the disclosure or non-disclosure of their IBD. These findings support the concept of the experience of disclosing chronic illness being somewhat of a double edged sword (Hays et al., 1992), and highlights it as an experience that is shared by adolescents as well as adults living with such conditions.

Existing literature argues that decisions relating to the disclosure of invisible conditions are complex and difficult to make (Dyck & Jongbloed, 2000; Joachim & Acorn, 2000; Fesko, 2001). This notion appears to be supported by two participants, who in discussing past and potential disclosure experiences, repeatedly spoke of their apprehension and ambivalence in talking to other people (both teachers and peers) about IBD. These young people's accounts of apprehension and ambivalence appear to resonate with general disclosure experiences described in mainstream literature (Altman & Taylor, 1973; Greene et al., 2006; Chaudoir & Fisher, 2010), where people are described as choosing whether to disclose based on their individual assessment of the associated physical and psychological costs and benefits of sharing such information. Consequently, these participants' experience of ambivalence and apprehension may reflect their uncertainty whether the anticipated rewards for disclosing their IBD to others are greater than the anticipated consequences (Altman & Taylor, 1973). Indeed, experiences of disclosure cited by the participants in this study

appeared to closely follow the pattern of such cost-reward assessments, with participants choosing to disclose in ways that addressed their needs (e.g. emotional support, freedom from psychological stress of suppressing a key identity, wanting to be known by others) whilst simultaneously avoiding disclosure related consequences (e.g. stigmatisation, reliving distress experienced at time of diagnosis, losing sense of control, normality, privacy and pre-illness identity). I will elaborate on this below.

Having disclosed their IBD themselves or having had their parents do this on their behalf, five participants discussed their fears of this resulting in news of their diagnosis being haphazardly spread to others at school. This finding differed from the Dyson et al. (2010) study exploring the disclosure of SCD at school, in that this study's participants spoke of these fears in relation to disclosure, whereas the participants' in the Dyson et al. (2010) study discussed this only in relation to non-disclosure. Similar to another study (Lightfoot et al., 1999), the young people in this study also appeared to have a strong desire to maintain their sense of privacy. In discussing experiences where they felt their privacy had been lost, four participants, spoke of feeling mortified and angry. Whilst other studies with people living with other chronic illnesses note the importance of maintaining a sense of privacy, the intense emotions experienced by these young people may relate to the very personal nature of the illness' symptoms. Young people in this study also spoke of feeling pressed to disclose and abandon their privacy when their condition became more visible and harder to conceal (e.g. due to visibility of symptoms, treatment, hospital appointments). This finding echoes other studies which found people with invisible chronic illnesses to be more inclined to disclose that which they felt incapable of hiding successfully (Hays et al., 1993; Mansergh et al., 1995; Troster, 1997; Gray et al., 2000; and Munir et al., 2005).

Whilst one hypothesis would be that participants' fear of news of their IBD being haphazardly spread and their intense reactions to losing their privacy may relate to their fear of stigmatisation (detailed discussion presented in section 4.2.1.1), these experiences may also relate, in part, to the experiences of powerlessness and lack of control described by many of these participants who found themselves in this position. Mainstream literature notes that feelings of 'loss of

control' as being a common experience for people living with chronic illnesses, one that is often a significant source of psychological stress (William, 1993; and Williams & Koocher, 1998). As chronic illness disrupts people's ability to predict medical events (Williams & Koocher, 1998), this experience of loss of control may be particularly heightened in those living with illnesses marked by periods of remission and relapse. For the participants in this study disclosure may offer an opportunity to acquire an internalised locus of control over their illness. For these young people, whose parents assume control over most aspects of IBD and its management, disclosure may feel like the sole source of their control over IBD. Therefore, participants' fears of news of their IBD being haphazardly spread and their intense reactions to losing their privacy may relate to concerns that they might lose their sole sense of control over their illness. This same fear might also be experienced when young people feel it necessary to surrender their privacy because of their inability to carry on hiding their IBD from others successfully. The need for the sense of control that disclosure offers may be particularly heightened for these young people, given their developmental stage and their experience of the many biopsychosocial changes associated with it.

In line with existing literature on adults with invisible conditions (Jackson et al., 2010), several participants discussed disclosing their IBD to others at school as liberating them from the psychological stress of concealing their IBD diagnosis. In addition to feeling liberated, three participants also spoke of feeling contained after having spoken to peers about their IBD. The feelings of guilt and deceit expressed by two participants in the study in relation to not having talked more about their IBD, support claims in existing literature that disclosure may alleviate the adverse psychological effects of suppressing and masking a central identity (Renfrew, 2004; Chaudoir et al., 2011). Indeed, these findings appear to highlight the existence of a reciprocal relationship between these young people attaining some degree of acceptance or 'ownership' of IBD and the process of disclosure. Therefore, similar to existing research with people living with HIV (Holt et al., 1998), whilst acceptance of IBD may facilitate disclosure, these young people's disclosure may also facilitate an acceptance of IBD by encouraging these young people to own their IBD more publicly. Consequently, these findings appear to be consistent with the parallels drawn by Myers (2004) between disclosure of sexual

orientation by GLB people and adults living with invisible chronic illnesses. As proposed by Myers (2004), the young people in this study appeared to operate on a continuum ranging from denial to self-acknowledgment to self-disclosure, and experienced disclosure as offering them a sense of relief and risk in terms of their personal and social worlds.

The existence of a reciprocal relationship between the acceptance of IBD and the process of disclosure appeared to be further supported by participants who spoke of their experiences of anger, frustration and disappointment in relation to the disabling reactions received following their repeated disclosure attempts to people at school. For these young people, who appeared to have accepted IBD as part of their identity, such incidents at school may have called into question more general definitions of self (Charmaz, 1983). Experiencing such disabling attitudes in response to their disclosing IBD may have raised afresh questions that they felt they had long put to rest about who they were in relation to others (Charmaz, 1983). These encounters may have been experienced as particularly distressing by these participants because they felt they had accepted their IBD, and furthermore, they thought themselves to be acceptable to the people around them at school (Charmaz, 1983).

In relation to psychological benefits experienced following disclosure of IBD to others at school, overall, the findings of this study echo existing literature which notes disclosure as offering increased access to emotional and social support to those with chronic illnesses (Dilorio et al., 1996; Lightfoot et al., 1999; Greene et al., 2006; and Jackson et al., 2010). However, given that most participants discussed feeling cared for and supported after having talked to people at school (teachers and peers) about their IBD, the experience of emotional support appeared to be most significant to these young people. From the transcripts it emerged that this emotional support helped participants to feel less isolated by the experience of living with a chronic illness. This emotional support may have also made them feel that people were not going to reject them or be disgusted as some may have originally feared (see detailed discussion in section 4.2.1.1).

Similar experiences of reduced loneliness were described by four participants who discussed talking to peers or members of staff at school (e.g. teachers, dinner lady) who had the same or similar diagnoses as they did. This finding parallels the experience of adolescents living with other invisible illnesses, where such disclosure was cited as helping adolescents to feel that they were not alone, and was noted as improving their overall sense of well-being (Bearison, 1991; Christian & D'Auria, 1997; Woodgate, 1998). Consequently, for the young people in this study, whether they talked to people who did or did not live with a similar condition to them, disclosure appeared to offer them a sense of belonging at a stage in their lives when the need to belong is particularly psychologically salient (Erikson, 1968; Kroger, 2000).

4.2.4 Summary

For the young people in this study talking about IBD after having transitioned from primary to secondary school appeared to be a complex and on-going experience which often involved the consideration of many variables. Key variables considered included: the degree to which these young people had accepted IBD as part of their emerging adolescent identities, and the potential psychological costs and rewards implicated in revealing an 'invisible' identity, one perceived to be prone to stigmatisation largely owing to the 'unpleasant' nature of IBD's associated symptoms.

The fear of disclosure, or non-disclosure, potentially leading to rejection from peers emerged particularly prominently from the young people's narratives. Whilst this in itself is not a novel finding, what was perhaps more noteworthy was that which seemed to feed into these fears, namely the 'unpleasant' nature of IBD's symptoms. The young people in this study experienced, and consequently managed, IBD as a stigmatised identity in its own right. The stigma associated with IBD appeared to relate specifically to participants' internalised social discourses around the social unacceptability of adolescents, in particular, talking about faeces and bowel movements (Diener, 2011). Disclosure strategies such as non-disclosure or partial disclosure were used by participants tactically and interchangeably to limit this potential threat of stigmatisation. Engaging in such disclosure often required participants to manage competing needs, such as the

need to prevent incontinence at school and the need to address peer curiosity with the need to protect themselves from stigmatisation and potential rejection. This suggests that young people with IBD experience similar, if not increased, complexity when choosing whether to talk about their illness, when compared to adult's experiences of disclosing 'invisible' conditions (Dyck & Jongbloed, 2000; Joachim & Acorn, 2000; Fesko, 2001). In addition, similar to existing research on young people's experiences of the management of less visible conditions (Wysocki, 1993) parental support in relation to disclosure of IBD to teachers in secondary school was welcomed. Whilst this alone might not be a novel finding, it highlights that, for these young people, parental support was experienced to support rather than oppose their sense of autonomy, because such parental support protected these young people against potential IBD related stigmatisation.

Overall, the young people in this study, experienced disclosure of IBD at secondary school to be a risky but potentially rewarding experience. For many young people choosing to disclose meant having to weigh the potential rewards against the anticipated costs of disclosure. Similar to existing research with adults (Altman & Taylor, 1973; Greene et al., 2006; Chaudoir & Fisher, 2010), this highlights the psychologically sophisticated processes that young people operate in order to talk about their IBD at school. This level of psychological maturity is further evident in the young people's discussions of the costs and rewards they associated with disclosing their IBD to others at school. In contrast with existing literature, (Dilorio, Hennessy, & Manteuffel, 1996; Greene et al., 2006; Dyson et al., 2010) aside from the practicality of needing to go to the toilet (which one might argue could have more to do with stigmatisation), the notion of disclosing to ascertain practical benefits is absent from these young people's narratives of disclosing their IBD at school. In general, participants in this study spoke at greater lengths about the psychological benefits and costs of disclosure than the practical advantages and consequences of disclosing IBD. What emerged in its place was talk of acquiring or avoiding complex psychological experiences. Psychological benefits included talking to address the need for their post-illness selves to be known by both themselves and others, and in order to attend to their need to belong. The psychological costs noted included loss of their privacy and

a sense of control over their lives and illnesses, and disabling attitudes from peers and teachers following disclosure. The degree to which disclosure and subsequent interactions supported or hindered these psychological experiences determined whether talking about IBD was experienced favourably or damagingly by these young people at secondary school.

Disclosure of IBD was experienced by the young people in this study against the backdrop of the many biopsychosocial changes associated with the time following transition to secondary school. In talking about their experiences of disclosing IBD during this particular stage of their lives, questions relating to these young people's identities emerged particularly prominently. Similar to existing literature with adults living with concealable conditions (Holt et al., 1998; Myers, 2004), for these young people there appeared to be two parallel continuums running between self-discovery and disclosure of IBD, whereby their disclosure seemed to simultaneously be affected by and effect young people's acceptance of their IBD. Consequently, many participants experienced a tension between acknowledging the reality of their illness and not wanting it to be a dominant and all defining part of their identity (Dyson et al., 2010). Similar to adults living with HIV (Holt et al., 1998), a couple of young people in the study experienced disclosure as potentially triggering the sense of trauma experienced in or around the time of their IBD diagnosis, and consequently these young people chose not to disclose to any of their peers at school. In addition to supporting the existence of a reciprocal relationship between acceptance and disclosure this finding also highlights that this is an experience shared not only by young people but by those living with non-life threatening chronic illness.

4.3 Psychological implications of the findings

In addressing the research questions (section 4.2), a core aim of this study was to explore, in-depth, the psychological implications of disclosing as a young person living with IBD and to address the main gaps in the literature (as highlighted in section 1.6). In the sections that follow, I will summarise the key psychological implications of the study, along with its core novel findings.

4.3.1 Distress

The overall experiences described by participants' in this study reflects the on-going and complex nature of making decisions relating to disclosure of IBD following the transition to secondary school. Participants spoke of experiences typically conceived to be psychologically taxing including managing a stigmatised identity (e.g. living in fear of peer rejection, balancing peer curiosity with stigma limitation), exploring and developing a relationship between their identities and illness against the backdrop of the many biopsychosocial changes associated with adolescence and starting a new school, dealing with the more negative costs associated with disclosure (e.g. surrendering privacy, enduring disabling attitudes and reactions from others). For instance, Heatherton et al. (2000) note individuals identifying themselves as belonging to a stigmatised group as often experiencing psychological distress. The significant role that stigma appears to play in participants' disclosure related decisions highlights the experiencing of disclosing IBD to others as one that may potentially place young people at increased vulnerability of experience psychological distress.

A particularly novel finding was that some participants experienced disclosure as being connected to the trauma they experienced in or around the time of diagnosis. Perhaps this experience is best understood against the backdrop of narrative therapy's conceptualisation of trauma, which argues that in engaging people in conversations realting to traumatic experiences risks their being re-traumatised by their original experiences (White, 2005). In addition to re-experiencing distress associated with trauma experiences, White (2005) notes that talking about traumatic experiences may serve to reinforce people to draw negative conclusions about their identities and lives which, consequently, may increase experiences of shame, hopelessness and despair. In choosing not to talk about their IBD at school for fear of re-living this experience of trauma, these participants further demonstrate the potential power disclosure may hold as a source of psychological distress for young people living with invisible illnesses such as IBD.

Therefore, whilst the period of transition from primary to secondary school is generally acknowledged as a time of increased stress (Seidman et al, 1994;

Sirsch, 2003), the findings of this study highlight unique and additional potential stressors for young people contemplating or having disclosing their IBD status at school.

4.3.2 Identity formation

As highlighted in section 4.2.2, in discussing their experiences of disclosure, these young people spoke in depth about the relationship between their emerging identities as adolescents and that of a young person living with IBD. Many participants experienced a tension between having IBD and wanting to be a 'normal' adolescent at school, which in turn affected the audience and the degree to which they disclosed illness-related information (i.e. increased disclosure appeared to relate to increased acceptance of IBD as part of adolescent identity and vice-versa). Whilst research with adults highlights that that living with a chronic illness may cause people to experience increased identity-related concerns (e.g. Charmaz, 1983), this study's findings go one step further in demonstrating that this experience is shared by young people living with chronic illnesses, specifically IBD. Additionally, given that participants' identities were noted as shaping and being shaped by the experience of disclosing IBD to others at school, this core finding also adds to the theoretical base by indicating disclosure as a tool for self-discovery for young people living with invisible illnesses such as IBD.

The results of this study show that disclosure of IBD was managed as a stigmatisable identity, and that participants' decisions to disclose to people at school were affected by internalised negative social discourses around the social unacceptability of faeces-related talk. These novel findings indicate that developing a preferred sense of identity may be increasingly complicated for adolescents living with and disclosing invisible illnesses such as IBD. Experiencing such illness and identity related struggles against the unique backdrop of having started a new school and having just entered a new psychosocial developmental stage, may also cause these young people to experience increased psychological distress. In addition, these findings also suggest that perhaps this 'struggle' with identity may translate into young people living with chronic illnesses, such as IBD, experiencing identity crises (Erikson,

1968) earlier or more intensely than perhaps those living without such a condition.

4.3.3 Social relationships

In discussing their experiences of disclosure and non-disclosure, concerns relating to social-image at school and friendship-maintenance appear relatively prominently in participants' accounts. Disclosure appeared to play a key role in these young people's experiences of forming and maintaining social relationships at school. Participants appeared to utilise non-disclosure or limited disclosure of IBD as a way of protecting and maintaining established friendships or preventing rejection from peers in general. Participants spoke of disclosing their IBD to others as relating to reduced experiences of isolation and loneliness and an increased sense of belonging, both of which are generally associated with better psychological outcomes (Qualter & Munn, 2002). These findings stress the fundamental importance of young people having the ability to use disclosure flexibly to meet both their psychosocial needs (e.g. the increased need for social belonging in adolescence), whilst simultaneously avoiding more negative psychosocial consequences (e.g. avoiding IBD related bullying and peer rejection).

In addition to the role disclosure played in young people's social relationship formation and maintenance, the findings of this study suggest that disclosure was experienced by participants as a means of maintaining a preferred public and private self-image. This finding confirms that, like adults (Schlenker, 1980; Chaudoir & Fisher, 2010) young people experience and are able to utilise disclosure in this manner. Additionally, given the reciprocal relationship identified between disclosure and acceptance of IBD as part of young people's identities, the study's findings also suggest that increased ability to disclose to others at school at this developmental stage may aid young people in developing a more psychologically comfortable relationship between their identities and living as a young person with a diagnosis of IBD. Therefore, overall, the findings of this study suggest that increased disclosure-related skills may improve young people's experiences of living with and managing IBD, which in turn may prevent potentially psychological distressing experiences (e.g. teasing) and increase

overall psychological well-being (e.g. having a congruent and positive sense of both their private and public identities).

4.3.4 Illness Management and (in)dependence

The findings of this study highlight disclosure as an important aspect of illness-management. However, overall, in participants' accounts of their experiences of disclosure conversations about disclosure in relation to illness management are noticeably lacking. In terms of disclosing IBD for more practical related reasons young people in this study mainly spoke about disclosing IBD to teachers to prevent accidents rather than to ensure their physical health needs were met and, on these occasions, it was these young people's parents who disclosed on their behalf to teachers. This novel finding suggests that utilising disclosure as a means of avoiding the stigma they perceived to be associated with IBD related talk and maintaining a 'normal' identity may be of more importance to young people at this developmental stage than engaging in disclosure for illness-management related reasons.

Given that most participants' spoke of their parents disclosing on their behalf for illness-management reasons (i.e. to prevent soiling themselves whilst at school), and whilst this may relate to practically and/or psychologically feeling underprepared to do so, these young people may perceive and experience illness-management to be their parents responsibility inside and outside of clinical settings, as do some young people living with other paediatric conditions, such as diabetes (Wysocki, 1993). Consequently, such young people run the risk of not being able to manage disclosure, a crucial part of the IBD management of their IBD. Long term, the implications of this mean that these young people may be more prone to engaging in risky health related behaviour (e.g. difficulties in treatment adherence). Add to this, as these young people progress further into adolescence their ability or desires to have parents speak on their behalf, inside and outside of school settings (e.g. medical appointments), may diminish.

4.3.5 General implications

Overall, the findings of this study stresses the psychological and clinical importance of disclosure in young people living with an invisible illness and

highlights it as an area professionals (psychologists, medical, teaching staff, and families) that should be given increased attention to.

4.4 Clinical and Service implications

4.4.1 Disclosure skills training and increasing peer support and belonging

As highlighted in the psychological implications section above (section 4.3), disclosure played a key role in participants' maintaining and forming social relationships at school. In addition to this, their ability to make assessments of various costs and benefits relating to disclosure of IBD appeared to be associated with preferable psychological outcomes for participants (e.g. increased feelings of belonging, reduced experiences of expected stigmatisation). With this in mind, similar to recommendations made for young people with diabetes (Dovey-Pearce et al., 2007), IBD services should adopt preventative and proactive approaches by offering young people courses or groups focused specifically on talking to others about living with IBD. Such courses or groups should be set-up to explore the concept of disclosure, provide advice and strategies on managing disclosure at school, as well as offer young people the opportunity to develop skills in weighing up the costs and benefits of doing this. Similar workshops have been run for GLB people (Morrow, 1996) and people living with mental health difficulties who were contemplating disclosure (Corrigan et al., 2013).

Given participants' strongly cited desires for increased feelings of belonging, reduced feelings of isolation, and the associated psychological benefits and costs of each, such groups would serve a dual function in that they would also provide young people with the opportunity to meet other adolescents in comparable circumstances, thereby increasing sources of informal support. Findings relating to the running of such groups (Grey et al., 2000) suggest that these groups could bolster young people's abilities to cope with IBD more generally, which could also translate into increased health related benefits (e.g. increased treatment adherence, reduced likelihood of stress induced IBD flare-ups).

4.4.2 Illness Management and (in)dependence

Most participants' spoke of their parents disclosing on their behalf for illness management reasons (i.e. to prevent soiling themselves whilst at school).

Findings of this study suggest that this may relate to young people feeling practically and/or psychologically underprepared to disclose themselves, and/or their perceiving and experiencing illness-management to be their parents' responsibility. Whilst the value of parental support with disclosure for the young people in this study was evident, such young people run the risk of not being able to manage disclosure, a crucial part of their IBD management. Additionally, as these young people progress further into adolescence their ability or desires to have parents speak on their behalf may diminish. Indeed, young people would be expected to take on increased responsibility for talking about their IBD with medical professionals as they get older and closer to being transitioned from paediatric to adult IBD services. In preparation for such a shift, services and professionals should consider making their practice more adolescent rather than parent-led. For instance, during appointments and consultations professionals should always endeavour to address the young person first, eliciting their views and feedback on their IBD before seeking their parents' thoughts. Young people should also be encouraged to attend all appointments and meetings involving their IBD (both at school and hospital). Doing these things will not only encourage young people to take more responsibility for disclosing their IBD to others, but will give them an opportunity to practice and become more comfortable in talking about their condition and its associated (potentially embarrassing) symptoms.

Given that this study highlights the important role parents' play in the disclosure of IBD to others services should advise parents on ways in which they could support their children in developing their own knowledge. This would help young people become less reliant on their parents to disclose on their behalves. Professionals should support this by signposting or advising parents on suitable resources that can be accessed to promote their child's understanding, for instance information provided by non-profit organisations like the NACC. Another way in which this might be addressed is through the running of regular post-diagnosis workshops or groups for parents. In addition to developing relevant knowledge and skills, such groups would allow parents the opportunity to meet parents in similar circumstances and for them to draw on their collective expertise. Services should consider the running of such groups for IBD,

particularly as similar groups are recommended for other paediatric chronic conditions, such as diabetes by the National Institute of Clinical Excellence (NICE, 2004).

Participants spoke of increased understanding of IBD, their own or that of their parents, as aiding disclosure to teachers and peers. Additionally, many participants spoke about the period in or around the point of diagnosis, in spite of not being specifically asked about this. Together, these two findings highlight the point of diagnosis as being a crucial time at which information should be shared with young people and parents alike. The findings of this study highlight the importance of young people being given developmentally appropriate information in relation to IBD. Results also suggest that some young people were unable or reluctant to fully understand the concept of chronicity. In light of this, it may be helpful for professionals and parents to explain what having a chronic illness means and for young people to be given some indication of what a future with IBD might look like. This may lessen any potential distress that might be experienced following diagnosis. It could also facilitate their ability and confidence to talk to others about IBD. Services may wish to think of alternative developmentally appropriate methods of providing such information, for instance putting information on CD ROMs, developing websites or specific computer packages which may be accessed at home.

4.4.3 Reducing psychological distress

4.4.3.1 Tackling disclosure disabling attitudes

All participants discussed not disclosing IBD for fear that this would lead to potential experiences of stigmatisation because of the 'unpleasant' nature of its symptoms. Greater awareness and understanding through public awareness campaigns, particularly those targeting people in schools, should be rolled out to reduce the social embarrassment and stigma associated with IBD. Such campaigns would serve to counter-act disabling responses following disclosure, such as those reported by the young people in this study (e.g. illness not being that bad, difference between IBD and Irritable Bowel Syndrome). Studies carried out with adults living with stigmatised conditions (Arboleda-Flórez & Sartorius, 2008; Corrigan et al., 2012) note public health campaigns as being an effective

way in which condition-related stigma may be tackled. Given participants' prominent fear that disclosing IBD would lead to rejection from peers, together with the fact that public awareness of IBD has been found to be especially low in young people (NACC, 2009), such campaigns should specifically target young people, as well as teachers and the general public. This recommendation fits the objectives outlined by the NACC's (2013) most recent strategic plans which include increasing awareness amongst the general public and focusing more closely on improving life for young people with IBD.

The disabling attitudes reported by some participants' following disclosure of IBD to teachers highlights the importance of fostering stronger links between IBD professionals and schools. Stronger links may further support efforts to reduce the stigma attached to IBD and could make it less difficult for young people to talk to peers about IBD. Gastroenterology services should consider developing specific outreach posts within their departments, similar to adult health teams, with such professionals taking on the responsibility for explaining and clarifying queries teaching staff may have in relation to a young person's IBD. Given participants' strong desire to feel in control of information shared with others, young people should be consulted as to what information is shared in such meetings. Young people may also be invited to attend or even chair such meetings jointly with professionals.

4.4.3.2 Addressing the tension between IBD and identity

The psychologically taxing experiences described by participants in disclosing IBD and, consequently, their potentially increased vulnerability to psychological stressors highlight the importance of psychological support for young people living with IBD. Services, if this is not already in place, should strongly consider increasing young people's access to psychological support within their services. Given that participants spoke of diagnosis as being a particularly psychologically stressful and difficult time, perhaps such support would be best introduced prior to or around the time of diagnosis. As all the young people in this study made reference to their emerging identities when talking about their experiences of disclosing IBD at school, post-diagnosis space should be offered with therapy to explore and develop a preferred relationship between their emerging adolescent

identities and IBD. Given participants reported experiences relating to 'loss of self' (Charmaz, 1983), for psychologists undertaking work with such young people it will be imperative to consider such issues. Narrative therapy may be especially suited to this task given its focus on how identity is co-constructed within the context of relationships with others, their history and culture (White & Epson, 1990). In addition to helping young people develop multiple and preferred identities, narrative therapy would also offer such young people an opportunity to deconstruct (Morgan, 2000) and consider wider internalised negative social disclosures (i.e. around the unacceptability of faeces related talk) which were found to influence participants' decisions to disclose. This may in turn improve both psychological well-being as well as increasing their freedom and ability to disclose IBD to others.

Findings relating to disclosure and potential 'loss of self' (Charmaz, 1983) also highlight the importance of professionals (teachers and medical professionals) and families acknowledging IBD as one of many aspects of young people's identities. Given that many young people in the study spoke about IBD not being their preferred dominant identity, it is imperative that professionals observe young people's conceivable desire to be viewed as separate to their IBD. One way of ensuring this within IBD clinic settings, where illness-related talk tends to dominate, is by professionals adopting an 'externalising approach' when talking to young people about their IBD. By personifying IBD and talking about it as though it were an external object (Nylund, 2000), professionals may thereby acknowledge people with IBD's commonly cited desire to be perceived as an individual and not be defined by their IBD (Carter et al., 2004). Such a strategy could serve the dual function of helping young people to talk about their illness and assisting them to accept or 'come to terms' with their illness (Knight et al., 2003). Whilst this has not yet been explicitly explored in young people with IBD, research carried out with young people with diabetes suggests that improved psychological adjustment to living with a chronic illness may increase treatment management and adherence (Wysocki et al., 2000; Northam et al., 2004), and may also enhance self-esteem and reduce behavioural difficulties (Jacobson et al., 1997).

4.4.3.3 Avoiding the re-living of trauma associated with diagnosis through IBD disclosure experiences

As the findings of this study highlight, some participants chose not to talk about their IBD at school for fear of re-living the sense of trauma they experienced in or around the time of diagnosis. Given this, it will be important to consider ways in which all types of professionals can foster a sense of safety when engaging young people in conversations relating to their IBD. Professionals working with young people with IBD should be advised to create a 'safe space' or position from which the young person may contemplate and talk about their experiences of IBD, so as to not experience this as being re-traumatising (Meiser-Stedman, 2002; White, 2005). One way in which this might be achieved is through explaining, reminding or offering confidentiality (if this is not a typical part of a professionals role, e.g. teachers) prior to inviting them to discuss aspects of their IBD. In doing this, professionals would be addressing participants' strongly cited desire to not lose their tight hold over IBD related information; another of the study's key and novel findings. By framing interactions as invitations for young people with IBD to share with them that which they feel comfortable in sharing may increase rapport and trust between professionals and such young people. Consequently, this may increase young people's desire to disclose illness information they may have originally felt to be embarrassed or scared (owing to stigma associated with IBD) to share, which in turn may improve practical and medical provision for their condition (e.g. appropriate medication to treat novel and perhaps embarrassing symptoms).

Again, these findings also point towards the suitability of narrative therapy as a therapeutic approach in working with such young people, given its focus on exploring the territories of identity available to people who have experienced trauma (e.g. helping people to identify skills and actions taken to minimise vulnerability and exposure to trauma), which in turn help people establish the sense of safety typically compromised by traumatic experiences (White, 2005).

4.4.4 Developmentally appropriate services and support

This study highlights the unique challenges and potential increased stressors experienced by young people living with IBD at this particular developmental stage.

The overall results highlight the importance of having developmentally appropriate support and services for young people with IBD. However, up until recently, non-NHS resources and support aimed specifically at young people with IBD have been scarce, with most having to rely on support developed for adults. Whilst this may relate to young people who are in the early stages of adolescence (like the participants in this study) not typically being considered to fall within the peak age of onset of IBD (between the ages of 15-30), this study supports the argument that it is simply not appropriate to extrapolate services and resources developed for adults and to apply these, without any biopsychosocial developmental consideration, to young people living with the same condition.

Whilst, within the last year the NACC, has made significant efforts to address this gap (e.g. planning the running of camps and workshops focused on helping young people to explore what it means to live with IBD) NHS and non- profit IBD organisations and services should increase their efforts to ensure that the support available meets the unique and additional needs of young people with IBD. For instance, whilst support groups exist for adults living with IBD in the UK, no such groups are currently in operation for adolescents living with the condition. Services should work together to consider ways in which they could address this gap. For instance, given the detailed psychosocial developmental knowledge psychologists possess, they could help set-up and/or run monthly support groups for adolescents with IBD, thereby ensuring such groups would be developmentally appropriate and that they would be addressing the unique issues highlighted by this study (e.g. fear of bullying, managing peer curiosity).

4.4.5 Raising overall awareness of the psychological and clinical importance of disclosure

Fundamentally, the findings of this study highlight the clinical significance of the act of disclosing IBD for young people. Both medical and non-medical professionals (e.g. psychologists, school teachers) should be mindful of its

importance in terms of illness-management and should consider disclosure not to be a one-off event, but view it instead as an on-going process requiring young people to frequently adapt in the face of new challenges. Therefore, professionals working in all settings (e.g. medical and school settings) should be encouraged to hold this notion in mind when developing service or tailoring the support they offer for young people living with IBD.

4.5 Reflexivity

As mentioned in chapters 2 and 3 (sections 2.4 and 3.2 respectively), within IPA a researcher's subjective bias to the data is recognised. To demonstrate the influence of this on the outcomes of this study, in the section that follows I will discuss this in greater detail.

4.5.1 Reflections on the research process

In the initial stages of interviewing I felt particularly anxious when participants began sharing what it was like for them to not talk about their IBD, construing this as participants going 'off topic'. This panic at times translated into my reverting to the use of closed rather than open questions. As I transcribed these early interviews I began to realise the saliency of these accounts in understanding participants' lived experiences. By accepting this as an important aspect of their experience, I felt more comfortable in permitting participants to privilege their experiences (Smith et al., 2009) and subsequently the use of more open ended questions increased across the remaining interviews. On reflection, it may have been helpful to carry out a pilot interview to help acclimatise myself with such experiences, however, the small sample population available impeded this.

Whilst participants were interviewed at the hospital around the time of scheduled outpatient appointments as this was thought to be more convenient for them, I am aware that this may have had its pitfalls. For instance, whilst interviews took place in private rooms in a different location to their outpatient appointments, I occasionally wondered if participants feared that perhaps staff might be listening in. In addition, given that some participants discussed disclosure within the context of diagnosis being a distressing experience, I realised that, for some, I may have been interviewing them in a building associated with unpleasant

experiences (e.g. medical procedures, diagnosis). This led me to contemplate whether interviewing participants at home might have elicited richer data. In addition to the paradox of a stranger asking them to disclose their experiences of disclosure, I was also aware that this may have been some participants' first time talking about IBD without the support of their parents. In an attempt to address these issues I ensured that I setup and approached interviews in a different manner, for instance arranging interview rooms in a more 'adolescent friendly' and less medical fashion, and by attempting to build rapport prior to the interview by engaging participants in conversations about their hobbies.

Although consent and assent was sought at several different points prior to the interview taking place and numerous reminders that non-participation would not affect care, given the hospital's strong reputation for conducting research I wondered if participation was in some way influenced by this. However, it is noted as being uncommon for people to participate in a study, unless they identify with and understand the study's validity and relevance (Patel et al., 2003). Indeed, all participants and their parents equally expressed a keenness to receive a document summarising key findings upon the study's completion. In addition, at the end of interviews many young people reported having enjoyed the experience of being interviewed.

On occasions, during interviews, I noticed myself feeling tempted to slip into two roles: that of a psychologist and someone who lives with IBD. Consequently, in spite of spending a considerable amount of time debriefing participants, after leaving some interviews, particularly those with participants whose experiences resonated with some of my own, I often contemplated how these participants felt. Again, in these instances, supervision proved to be an invaluable asset in bracketing (Smith et al., 2009) my own experiences from those belonging to participants.

4.5.2 Reflections on the impact of my IBD on the overall conduct of the study

Whilst I strove to ensure throughout the research process that my own experiences of living with IBD did not colour the research, holding in mind the principle of the double hermeneutic involved in IPA (refer to section 2.2), it is

worth reflecting on the different ways this may have impacted on the overall conduct of this study. Whilst I conducted the literature review in a systemic manner, I may have prioritised aspects of studies which fit with ideas and hypotheses shaped by my own experiences of living with IBD. For instance, during an IPA peer supervision session my inclination towards the negative implication of disclosing IBD was brought to my attention. Subsequently, I utilised this knowledge to ensure that all participants were offered a space to talk about both positive and negative experiences and revised my literature review to ensure that I made reference to such experiences.

While I attempted to remain mindful of how my own IBD diagnosis impacted on the interview process (e.g. regularly asking participants to explain what they meant when they used certain phrases to describe similar experiences to my own, rather than making assumptions), on reflection my decision to not disclose my IBD diagnosis to participants may have inadvertently affected this. I feared that doing so would affect the interview process, and more specifically, I believed that doing so would risk privileging my experience over participants' own experiences. Consequently, I chose not to disclose my diagnosis of IBD unless directly asked by participants. On reflection, I now wonder if by doing this I abandoned my key asset as a researcher in this field, particularly given my participants' relatively young ages. However, more importantly I wonder if this impacted on participants' experiences of the interview process, and ultimately the findings of this study. I now wonder if during interviews, participants held back from talking about their experiences in greater detail, particularly talk relating to IBD and its symptoms. Given the findings that emerged in relation to stigma and faeces related talk, this may have well been the case. Whilst this 'holding back' may have related to my other characteristics as a researcher (e.g. my age, gender, culture or professional identity as a psychologist), in these instances I now wonder whether my disclosing my condition to participants would have yielded different results.

My decision to disclose my condition to the readership was influenced by the importance placed upon transparency in qualitative research (Yardley, 2008), particularly IPA. I hoped that in doing this I would remain open, mindful and

reflective throughout the research process of the possible impact my IBD could have on the overall study. However, it is worth acknowledging that whilst I engaged in many activities to ensure that as far as was possible I 'bracketed off' my own IBD related experiences when analysing and discussing this study's findings (e.g. reflecting on this frequently with professionals and peers in supervision sessions, ensuring that results were grounded in participants' experiences and the analysis grounded within a theoretical framework), another person conducting this study (living with or without IBD) may have analysed and presented a different set of data. For instance, they may have chosen to conceptualise many of participants' experiences of disclosing IBD by focusing on the experience of shame rather than stigma. Aside from my IBD, it is also worth noting my preference for and familiarity with the narrative therapy approach (refer to self-reflexivity, section 2.6), and the influence this may have had on the psychological theories and knowledge bases I drew upon in conceptualising my findings presented in this discussion chapter (Chapter 4).

4.6 Issues of reliability and validity

To ensure its quality and rigour, the study was guided by the four principles set out by Yardley (2008). In the section that follows I will discuss each of these issues and how these were addressed.

4.6.1 Sensitivity to context

The two ways in which, according to Yardley (2008), one can demonstrate that a qualitative study is sensitive to context are described in the sections that follow.

4.6.1.1 *Consideration of relevant theoretical and empirical literature*

The theoretical and empirical literature relevant to this study is outlined in the literature review within the introduction (Chapter 1). Reviewing relevant literature highlighted gaps in current understanding, thereby facilitating the conception of a relevant and suitable research question. The approach to data analysis in this study is explained and justified on this basis in Chapter 3. The discussion presented in section 4.7 outlining the contribution of this study's findings to future clinical practice is further evidence of this.

4.6.1.2 *Sensitivity to perspective and socio-cultural context of participants*

During the course of the research I attempted to remain mindful of the participant's perspectives and socio-cultural settings. My characteristics as the researcher (e.g. age, gender, culture, professional identity and IBD diagnosis) and the setting in which the research took place were considered and reflected upon throughout, as evidenced in the reflecting diary (sample entry in Appendix 13) and the section of on self-reflexivity in chapter 2 (section 2.6). Given that I shared a diagnosis of IBD with participants, special attention was paid to this context so as to ensure that my fore-understanding or presumed sensitivities did not hinder the following-up of participants' statements. Throughout each interviews I remained mindful of potential power imbalances that could transpire, particularly when one is positioned by another as the 'expert'. In attempt to address this, participants' perspectives were privileged through the use of open-ended questions.

4.6.2 Commitment and rigour

The four key influences in this area are said to include: methodological competence, in-depth engagement with the topic, thorough data collection, and the depth and breadth of analysis (Yardley, 2008). The disclosure of invisible conditions, particularly by young people, is an area that I am interested in on both a professional and personal level. Additionally, as a psychologist who has a preference for psychological approaches that position people as experts on their own experiences, I aspired throughout this study to present the voices of participants, so that their voices could be heard and used to inform clinical practice. I strove throughout to conduct a comprehensive study and to present a rich and broad analysis. I also endeavoured to reflect the multiple personal perspectives that may have impacted upon this study (e.g. researcher, clinician and someone who lives with IBD). As highlighted in Chapter 2, at the planning stage this study went through scrutiny from three separate research proposal boards and research ethics committees. Feedback from my supervisor during the analysis stage was utilised as a 'credibility check'. Participant feedback on the analysis was not sought as this was not felt to be appropriate. Giorgi (2008) argues that member checking is misplaced and not trustworthy, as participants do not have the appropriate skills to adequately review the phenomenological

analysis, and consequently are unable to confirm the meaning of their experiences. In terms of methodological competence, in addition to consulting a range of relevant literature, I also attended a two day IPA workshop and speciality lectures in an attempt to develop my knowledge and skills in this area.

4.6.3 Coherence and transparency

The coherence of a study is, “the extent to which it makes sense as a consistent whole” (Yardley, 2008, p. 248). A comprehensive rationale for this research is outlined in Chapter 1, whilst the theoretical background of IPA, and why it was deemed appropriate and chosen over other qualitative methods is discussed in Chapter 2 (sections 2.2.1 and 2.2.2). I endeavored to make the process and the analysis itself as clear as possible by providing an audit trail of the analysis process (Appendices 10-12). I also provided relevant supporting extracts so that others may personally review the analysis and draw their own conclusions (Elliott et al., 1999; Yardley, 2008). Furthermore, peer review and discussions with two supervisors, one specialising in paediatrics and the other in qualitative research, were utilised to enable emerging themes, along with similarities and differences, to be noted. Along with allowing me to consider alternative perspectives, this gave me an opportunity to reflect on how my own assumptions and biases may have been influencing the data. The reflexivity adopted throughout this study has also been a salient aspect of its transparency. A reflexive journal (Appendix 13) was kept during the course of the study. An excerpt from this, along with a section on self-reflexivity in Chapter 2 (section 2.6) were included to demonstrate, as far as is possible, the assumptions, values and interests that I hold and the effects these may have had on the research process (Elliott et al., 1999).

4.6.4 Impact and importance

Yardley (2008) posits that unless a study’s findings has the potential to make a meaningful difference, that there is no value in conducting such research. The relevance and need for this study is outlined in the literature review (Chapter 1). Furthermore, I would hope this research adds to the understanding of how young people with invisible illnesses, those living with IBD in particular, experience talking about their invisible conditions whilst at school. The three ways in which I

anticipate this study will have impact and contribute include: (a) in its guise as a thesis, this study will become a public document; (b) its findings will be disseminated further in a journal article; (c) findings will be presented to the gastroenterology team that aided with recruitment during one of the team's allocated research seminars.

4.7 Methodological considerations

4.7.1 Limitations of IPA

As highlighted in section 4.4 of this chapter, an analytic account in an IPA study will be shaped by the perspective, and subsequently the interpretations, of the researcher conducting the study. This, along with the open nature of IPA guidelines, may leave people feeling sceptical of any claims concerning the significance of an IPA study's findings (Pringle et al., 2011). Consequently, findings have been described as inciting a sense of discovery rather than construction (Willig, 2001). However, Smith et al. (2009) argue that audit is present to, "Ensure that the account produced is a credible one, not that it is the only credible one" (p. 183). Add to this, Willig (2001) claims that the flexibility of guidelines provide an element of creativity and freedom. Pringle et al. (2011) note may be necessary in attaining the views of participants who are considered to be difficult to reach (e.g. young participants).

The role of language plays in IPA studies also presents certain difficulties. IPA is dependent upon participants' use of language to describe their experiences. One argument is that IPA participants may not have the ability to communicate the subtleties and nuances of their experience, and consequently may be unable to convey the rich nature of their experience through the medium of language (Willig, 2001). This might be especially so for younger participants. Whilst Smith and Osborn (2008) acknowledge that participants may find it difficult to articulate their thoughts and feelings, they contend that in IPA it is the participants' inner states ought to be interpreted by the researcher, through a detailed analysis of that which is said and that which is not said.

An additional criticism comes from social constructionists who maintain that meaning can only be constructed through language, as they perceive there to be no 'reality' without the presence of language (Berger & Luckmann, 1966). Consequently, they argue that IPA fails to consider the role language plays in constructing reality (Potter & Wetherell, 1987). However, within IPA it is recognised that access to pure experience is never possible (Potter & Wetherell, 1987). IPA, therefore, challenges the restricted notion of people as simple discursive agents, and emphasises that as an approach it is mainly interested in how a participant experiences the world, rather than the truth of the reality (Eatough & Smith, 2006). Therefore this study, as an IPA analyses, is posited to be an interpretation of participants' lived experiences, rather than a reflection of these participants' realities (Willig, 2008).

4.7.2 Generalisability

Whilst numerous common elements were detected in the narratives of the young people's experiences of disclosing IBD, it should also be noted that the sample used for this study had several finite characteristics. Most participants were aged between 12 and 13 years old and, with the exception of two participants, participants were mostly white British. All attended mainstream schools in the UK and lived at home with at least one parental figure. They were recruited by members of the gastroenterology team who knew them and deemed them suitable to participate. All participants were willing to take part in this study. A study on this topic carried out by another researcher or one which recruited participants with alternative characteristics may have resulted in different findings. This means that any generalisations made from this study should be cautious and limited. Whilst the results reflect the experiences of the group studied, young people at different stages of schooling and development and those from different cultural backgrounds may have contrasting experiences. Consequently, further studies are required prior to any wider conclusions being drawn.

4.8 Future research

This study indicates key areas for further research. As the present study focused on participants aged 12 to 13, it would be of benefit to explore young people's

experiences of disclosing their IBD at different stages of development. Additionally, given that most participants described themselves as being white British, a further study exploring the cultural influence on young people's experiences of disclosure would be beneficial, particularly as this is an area within chronic illness which tends to be overlooked (Woodgate, 1998). Another area might be to explore parents role in managing their children's IBD. Existing research overlooks parental involvement in relation to paediatric IBD. However, as highlighted in this study by their involvement in their children's accounts of disclosure, their involvement may be significantly influential. Exploring this further may assist services to better facilitate parents involvement in the management of paediatric IBD.

A further study is needed to explore the notion of IBD as a stigmatisable identity in greater depth. It would be interesting to consider whether this is an experience shared by all people living with IBD, both young and old. A study researching this in greater depth may highlight additional and novel ways in which such stigma might be tackled. Given that for the participants in the study there appeared to be some resonance between disclosure and the period in or around the time of diagnosis, it would also be interesting to explore young people's experiences of being diagnosed with IBD. A study along these lines could highlight ways in which services might lessen potential distress associated with diagnosis.

4.9 Conclusion

The research focused on young people with IBD and their experiences of disclosing IBD at school, following the transition from primary to secondary school. It was an in-depth study of seven adolescents which explored their experiences and understanding of disclosing their IBD diagnosis to peers and school professionals. The study found that for the young people talking about IBD at school was a complex and on-going experience which involved the consideration of many variables. Internalised social discourses around the unacceptability of talking about IBD's symptoms, namely diarrhoea, meant that IBD was experienced and managed by the young people as a stigmatised identity. Non-disclosure and partial disclosure strategies were used by participants tactically and interchangeably to limit potential stigmatisation and

rejection and often required participants to manage competing needs. Parental support with disclosing IBD to teachers was experienced by the young people as supporting their sense of autonomy.

Disclosure was experienced as a risky but potentially rewarding experience, which involved having to weigh-up potential rewards against anticipated costs. Psychological benefits discussed included: talking to address the need for their post-illness selves to be known by both themselves and others, and to belong. The psychological costs noted included: not talking to maintain their privacy and a sense of control over their lives and illnesses, and to avoid disabling attitudes and responses from peers and teachers. Experiencing disclosure against the backdrop of the many biopsychosocial changes associated with the time following transition to secondary school raised questions relating to these young people's identities. A reciprocal relationship between self-discovery and disclosure of IBD was noted, whereby disclosure seemed to simultaneously be affected and affect acceptance of IBD. Consequently, many described experiencing a tension between acknowledging the reality of their illness and not wanting IBD to be a dominant and all defining part of their identity. Some participants experienced disclosure as potentially triggering the sense of trauma experienced in or around the time of their IBD diagnosis, and consequently opted not to disclose to any of their peers.

These findings call for services and professionals in all settings (medical and school settings) to consider disclosure of IBD in a more holistic manner, as an on-going process requiring young people to regularly adapt in the face of new challenges, and to adapt their services and practices accordingly.

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APPENDICES

- 1 Literature search strategies
- 2 Confirmation of ethical approvals:
 - a. Ethical approval from University of East London
 - b. NHS ethical approval
 - c. Ethical approval from hospital's clinical research adoption committee
 - d. Local research at development team approval
- 3 Invitation letter
- 4 Parent information sheet
- 5 Young person's information leaflet
- 6 Consent forms for parents
- 7 Assent form for young people
- 8 Interview schedule
- 9 Audit trail: Sample of analysed transcript (Interview 2 – Tyler)
- 10 Audit trail: Emerging themes in chronological order (Interview 2 - Tyler)
- 11 Audit Trail: Clustered themes and superordinate themes (Interview 2 – Tyler)
- 12 Audit Trail: Super-ordinate themes clustered and master themes for all interviews:
 - a. Super-ordinate themes clustered and master themes for all interviews
 - b. Themes from all interviews
- 13 Extract from reflective diary
- 14 Synopsis of participants experiences of disclosure and illness
- 15 Modifications to text
- 16 Additional information sheet given to participants after interviews

Appendix 1 – Literature search strategies

Search strategies for the literature review

A literature search was conducted to identify relevant books and papers to this study. Electronic databases PSYCHInfo, CINAHL, Education Research Complete and Web of science were the main databases utilised. Google Scholar was also scanned for key words and books relevant to the study were also included. Additionally, journal articles and books cited in the literature reviewed and considered to be potentially pertinent to this study were followed-up and included, if upon further reading these were considered to be relevant.

The term “Inflammatory Bowel Disease” and its synonyms were entered into the electronic databases above, coupled with the terms “talking”, “invisible illness” and “young person” and their synonyms. The results of this search were then combined with the terms “transition in school”, “friends” and “teachers” and related synonyms. As demonstrated in the table below, this did not yield many, in some cases any, results. Therefore the search was expanded to include terms associated with other invisible illnesses (e.g. AIDS, diabetes). As this also produced limited results, the search was expanded to include the term “adults” and its synonyms.

Papers were chosen for potential inclusion if they offered empirical data on the experiences of people with chronic illnesses disclosing to others (e.g. people disclosing to peers or partners), as opposed to the disclosing of information to people with chronic illness by others (e.g. professionals disclosing medical conditions to their patients). Due to the relatively large body of literature identified by the last searches which included the terms relating to “adults”, meta-analyses and systematic reviews were prioritised over papers reporting on single studies. Qualitative studies were prioritised over quantitative studies and, where available, preference was shown to studies carried out in the UK.

Table 1: Range of publication dates included in database searches

	Years included in searches
PSYCH Info	1981-2013
CINAHL	1964-2013
Education Research Complete	1964-2013
Web of science	1970-2013

Key

: *Truncation is represented by an asterisk (*). This creates searches where there are unknown characters, multiple spellings or various endings. Databases then find all forms of that word. E.g. type comput* to find the words computer or computing.

“ ”: when a phrase is enclosed by ***double quotations marks***, the exact phrase is searched

[Smart text search]: SmartText Searching leverages a technology that summarizes text entered to the most relevant search terms then conducts search. This search mode was not available for all databases.

Table 2: Results of database searches

Numbers	Terms	PSYCH Info	CINAHL	Education Research Complete	Web of science
S1	IBD	239	916	90	12,351
S2	“Inflammatory Bowel Disease”	388	2,000	125	40,191
S3	Colitis*	712	3,547	213	53,810
S4	“Crohn’s disease”	318	1,912	118	24,068
S5	“Ulcerative colitis”	478	1,470	65	32,728
S6	“Indeterminate colitis”	3	21	3	615
S7	“Chronic illness”	10,907	4,056	1,677	8,963
S8	“Chronic health condition”	94	101	29	171
S9	“Long term illness”	185	211	43	392

S10	“Invisible illness*”	8	9	2	3
S11	“Less visible illness*”	1,201	498	313	0
S12	“Less visible condition*”	301	456	350	0
S13	“Invisible disability*”	6	18	10	19
S14	“Less visible disability*”	238	435	1,471	0
S15	Talk*	5,814	13,114	37,142	64,735
S16	Tell*	3,831	7,754	17,919	75,781
S17	Disclose*	1,618	2,834	3,278	31,473
S18	Disclosure	3,235	11,296	5,013	20,369
S19	Share*	13,979	23,895	40,697	263,546
S20	“Information sharing*”	248	506	1,231	4,939
S21	“Information management*”	399	9,245	8,548	8,190
S22	Inform*	85,656	265,320	467,472	1,582,748
S23	“Disclosure decisions*”	359	32	15	92
S24	“Disclosure decision making*”	13,110	12	6	19
S25	Child*	14,918	398,618	712,837	1,042,253
S26	Adolescent*	6,052	57,822	70,109	205,921
S27	“Young person*”	359	662	7,916	1,713
S28	Youth	13,110	15,008	228,601	64,510
S29	Teen*	14,918	9,568	55,551	22,468
S30	Teenager*	6,052	3,185	43,335	10,032
S31	Juvenile	42,448	6,859	85,799	109,093
S32	“Young adult*”	26,841	64,684	36,092	62,446
S33	Transition*	42,932	18,516	29,057	1,019,431
S34	School	728,743	63,207	1,196,541	284,240
S35	Education	428,950	389,620	1,368,994	413,621
S36	“secondary school”	10,969	1,101	17,273	8,496
S37	“primary school”	6,577	1,241	31,345	8,230
S38	“middle school”	11,415	2,672	23,780	6,594
S39	“School transition”	1,549	43	217	204
S40	“Transition to secondary school”	56	10	71	39

S41	“Transition to secondary education”	9	2	25	21
S42	“Transition to high school”	403	14	281	59
S43	“Educational transition”	37	3	40	50
S44	"move* to secondary school"	5,244 [Smart text search]	6685 [Smart text search]	12	425 [Smart text search]
S45	Adults	319,041	74,212	148,254	816,766
S46	Men*	734,591	227,402	265,423	932,038
S47	Women*	201,789	161,098	109,809	724,726
S48	Partners*	43,122	24,802	39,304	99,073
S49	Peers*	32,772	6,262	14,119	25,246
S50	Friends*	31,746	9,931	20,382	33,264
S51	“School friends**”	141	24	81	84
S52	“School-based friendships”	1	149 [Smart text search]	1	1
S53	Classmates	3,015	302	2,608	1,550
S54	“Romantic interests”	18	2	5	11
S55	Boyfriend	701	130	489	465
S56	Girlfriend	502	68	352	397
S57	Teachers*	117,935	12,978	336,465	70,170
S58	Professionals*	62,679	46,311	32,449	72,719
S59	“School Professionals**”	356	46	203	92
S60	HIV*	33,708	58,819	9,709	237,641
S61	“Human immunodeficiency virus”	4,393	8,500	2,895	94,253
S62	AIDS*	38,708	38,765	42,217	138,872
S63	“Acquired immune deficiency syndrome”	2,927	562	3,001	3,917
S64	“irritable bowel syndrome”	1,043	2,601	72	11,977
S65	Cancer	43,920	151,417	12,742	1,231,196
S66	“breast cancer”	7,294	27,642	1,919	262,742

S67	“prostate cancer”	1,492	9,174	360	98,628
S68	Leukaemia	1,432	1,301	2,296	241,598
S69	Epilepsy	24,115	9,198	1,361	85,419
S70	Stroke	19,937	49,073	1,879	169,593
S71	Scleroderma	76	2,133	24	12,988
S72	“Sickle cell”	962	3,072	560	19,145
S73	Diabetes	16,898	91,609	3,967	307,500
S74	“Mental conditions”	5,459	63	36	217
S75	“mental illness”	27,958	9,888	9,954	18,919
S76	“mental disorders”	88,439	34,931	11,563	19,589
S77	“rheumatoid arthritis”	1,996	9,570	301	106,001
S78	Autism*	38,480	7,685	11,657	25,523
S79	Arthritis	4,594	24,535	1,232	160,819
S80	“Chronic Fatigue Syndrome”	1,816	1,342	259	5,557
S81	Fibromyalgia	2,007	3,863	120	9,727
S82	“Chronic Myofascial Pain”	37	27	1	76
S83	Depression	173,618	72,883	17,164	265,302
S84	“Celiac Disease”	141	2,303	125	12,840
S85	“Ehlers Danlos Syndrome”	30	269	18	2,345
S86	“HyperMobility Syndrome”	26	74	9	307
S87	“Chronic Migraines”	13	6	1	15
S88	Infertility	2,216	5,457	465	34,098
S89	Lupus	952	5,360	460	70,689
S90	“Lyme Disease”	176	1,368	203	8,251
S91	“Multiple Sclerosis”	8,454	11,435	403	67,794
S92	“Neurological Diseases”	1,492	330	64	5,777
S93	“Sjogren’s Syndrome”	101	1,135	12	6,428
S94	“Thyroid Disorders**”	413	183	11	1,555
S95	“Hypothyroidism”	1,069	2,571	218	19,285
S96	“Cushing’s Disease”	112	58	13	1,778

S97	IBD Words S1 or S2 or S3 or S4 or S5 or S6	1201	6,171	327	88,314
S98	Invisible illness words S7 or S8 or S9 or S10 or S11 or S12 or S13 or S14	12,403	5,019	3,551	9,483
S99	Talking words S15 or S16 or S17 or S18 or S19 or S20 or S21 or S22 or S23 or S24	107,559	311,095	547,406	1,974,208
S100	Young people words S25 or S26 or S27 or S28 or S29 or S30 or S31 or S32	207,032	485,742	822,327	1,310,422
S101	Transition in school S33 or S34 or S35 or S36 or S37 or S38 or S39 or S40 or S41 or S42 or S43 or S44	991,628	447,223	1,785,298	1,638,457
S102	Adult words S45 or S46 or S47 or S48	1,077,199	413,175	500,428	2,192,599
S103	Friends words S49 or S50 or S51 or S52 or S53 or S54 or S55 or S56	64,270	16,089	36,503	58,307
S104	Teacher words S57 or S58 or S59	177,114	58,606	364,537	141,335
S105	Other invisible illnesses S60 or S61 or S62 or S63 or S64 or S65 or S66 or S67 or S68 or S69 or S70 or S71 or S72 or S73 or S74 or S75 or S76 or S77 or S78 or S79 or S80 or S81 or S82 or S83 or S84 or S85 or S86 or S87 or S88 or S89 or S90 or S91 or S92 or S93 or S94 or S95 or S96	500,405	530,901	110,279	2,922,905
S106	IBD & Talking S97 and S99	27	403	45	3,476

S107	IBD & Talking & young person S106 and S100	7	530,901	22	399
S108	IBD & invisible illness S97 and S98	70	25	12	123
S109	IBD & invisible illness & young person S108 and S100	12	7	8	54
S110	IBD & Talking & Invisible illness S97 and S99 and S98	12	6	2	22
S111	IBD & Talking & Invisible illness & young person S99 and S109	0	1	2	11
S112	IBD & Talking & Invisible illness & young person & transition in school S111 and S101	0	398	2	3
S113	IBD & Talking & Invisible illness & young person & transition in school & friends S112 and S103	0	8	0	0
S114	IBD & Talking & Invisible illness & young person & transition in school & friends & staff S113 and S104	0	0	0	0
S115	Other illnesses & Talking & young person S105 and S99 and S100	4,718	8,713	9,395	22,094
S116	Other illnesses & Talking & Invisible illness & young person S115 and S98	66	83	107	261

S117	Other illnesses & Talking & Invisible illness & young person & transition in school S116 and S101	42	20	59	90
S118	Other illnesses & Talking & Invisible illness & young person & transition in school & friends S117 and S103	2	1	4	15
S119	Other illnesses & Talking & Invisible illness & young person & school & friends & staff S118 and S104	2	1	2	5
S120	Other illnesses & Talking & Invisible illness & adult S105 and S99 and S98 and S102	144	186	158	472
S121	Other illnesses & Talking & adult S105 and S99 and S102	10,036	18,563	9,390	56,708

Appendix 2- Confirmation of ethical approvals

(a) Ethical approval from University of East London

ETHICAL PRACTICE CHECKLIST (Professional Doctorates)

SUPERVISOR: Ken Gannon

ASSESSOR: Ian Wells

STUDENT: Emma Micallef

DATE (sent to assessor): 25/02/2012

Proposed research topic: Talking about an invisible illness: The Experience of Young People suffering from Inflammatory Bowel Disease (IBD)

Course: Professional Doctorate in Clinical Psychology

1. Will free and informed consent of participants be obtained? **YES / NO**
2. If there is any deception is it justified? **YES / NO / N/A**
3. Will information obtained remain confidential? **YES / NO**
4. Will participants be made aware of their right to withdraw at any time? **YES / NO**
5. Will participants be adequately debriefed? **YES / NO**
6. If this study involves observation does it respect participants' privacy? **YES / NO / NA**
7. If the proposal involves participants whose free and informed consent may be in question (e.g. for reasons of age, mental or emotional incapacity), are they treated ethically? **YES / NO / NA**
8. Is procedure that might cause distress to participants ethical? **YES / NO / NA**
9. If there are inducements to take part in the project is this ethical? **YES / NO / NA**
10. If there are any other ethical issues involved, are they a problem? **YES / NO / NA**

APPROVED

YES	YES, PENDING MINOR CONDITIONS	NO
------------	--------------------------------------	-----------

MINOR CONDITIONS:

REASONS FOR NON APPROVAL:

Assessor initials: ~IW Date: 20/7/12

RESEARCHER RISK ASSESSMENT CHECKLIST (BSc/MSc/MA)

ASSESSOR: Ian Wells

DATE (sent to assessor): 25/02/2012

Proposed research topic: Talking about an invisible illness: The Experience of Young People suffering from Inflammatory Bowel Disease (IBD)

Course: Professional Doctorate in Clinical Psychology

Would the proposed project expose the researcher to any of the following kinds of hazard?

- | | | |
|----|--|-----------------|
| 1. | Emotional | YES / NO |
| 2. | Physical | YES / NO |
| 3. | Other
(e.g. health & safety issues) | YES / NO |

If you've answered YES to any of the above please estimate the chance of the researcher being harmed as: HIGH / MED / LOW

APPROVED

YES	YES, PENDING MINOR CONDITIONS	NO
-----	----------------------------------	----

MINOR CONDITIONS:

REASONS FOR NON APPROVAL:

Assessor initials: **IW** Date: 20/7/12

Please return the completed checklists by e-mail to the Helpdesk within 1 week.

SCHOOL OF PSYCHOLOGY

Dean: Professor Mark N. O. Davies, PhD, CPsychol, CBiol.



School of Psychology Professional Doctorate Programmes

To Whom It May Concern:

This is to confirm that the Professional Doctorate candidate named in the attached ethics approval is conducting research as part of the requirements of the Professional Doctorate programme on which he/she is enrolled.

The Research Ethics Committee of the School of Psychology, University of East London, has approved this candidate's research ethics application and he/she is therefore covered by the University's indemnity insurance policy while conducting the research. This policy should normally cover for any untoward event. The University does not offer 'no fault' cover, so in the event of an untoward occurrence leading to a claim against the institution, the claimant would be obliged to bring an action against the University and seek compensation through the courts.

As the candidate is a student of the University of East London, the University will act as the sponsor of his/her research. UEL will also fund expenses arising from the research, such as photocopying and postage.

Yours faithfully,

Dr. Mark Finn

Chair of the School of Psychology Ethics Sub-Committee

Stratford Campus, Water Lane, Stratford, London E15 4LZ
tel: +44 (0)20 8223 4966 fax: +44 (0)20 8223 4937
e-mail: mno.davies@uel.ac.uk web: www.uel.ac.uk/psychology



INVESTOR IN PEOPLE



The Government Standard

The University of East London has campuses at London Docklands and Stratford
If you have any special access or communication requirements for your visit, please let us know. MINICOM 020 8223 2853



Appendix 2- Ethical approvals

(b) NHS ethical approval



NRES Committee London - Bromley

Bristol Research Ethics Committee Centre
Whitefriars
Level 3, Block B
Lewins Mead
Bristol
BS1 2NT

Telephone: 0117 342 1387
Facsimile: 0117 342 0445

23 July 2012

Miss Emma Micallef
Trainee Clinical Psychologist
Camden and Islington Mental Health NHS Trust
UEL, School of Psychology
Stratford Campus, Romford Road London
E15 4LZ

Dear Miss Micallef

Study Title: Talking about an invisible illness: The Experience of Young People with Inflammatory Bowel Disease
REC reference: 12/LO/1112
Protocol number: n/a

The Research Ethics Committee reviewed the above application at the meeting held on 19 July 2012. Thank you for attending to discuss the study.

Documents reviewed

The documents reviewed at the meeting were:

Document	Version	Date
Covering Letter		19 June 2012
Evidence of insurance or indemnity		21 June 2012
Interview Schedules/Topic Guides	1	18 June 2012
Investigator CV		
Letter of invitation to participant	1	18 June 2012
Other: CV for academic supervisor		
Other: UEL requesting amendments to Registration Documents		26 January 2012
Other: Responding letter having made the amendments to the Registration Documents		05 February 2012
Other: Approval of Registration Document after Amendments to application forms		23 February 2012
Other: [redacted] Hospital's CRAC Team's requesting amendments to application form		23 February 2012
Other: Responding letter having made the amendments to CRAC application form for [redacted] Hospital		21 May 2012
Participant Consent Form: Young person consent form	1	18 June 2012
Participant Consent Form: Parent/guardian consent form	1	18 June 2012
Participant Information Sheet: Young person and parent/guardian	1	18 June 2012

information sheet		
Protocol	1	18 June 2012
REC application		

After the Committee's initial discussions you were invited to join the meeting to clarify the following issues:

- The Committee advised that the NRES website should be consulted for advice on how to re-word the consent / assent forms (<http://nuhrise.org/wp-content/uploads/NRES-Guidance-on-Information-Sheets-and-Consent-Forms.pdf>).
- The Committee stated that the PIS for 12 year old children should be simplified and advised that the PIS is tested on a group of 12 year old children.
You replied that you are working with children from [REDACTED]
- The Committee stated that there should be an additional statement on the Consent Form to consent to the use of anonymised quotes.
- The Committee asked if there was an opportunity for boys to be interviewed by a male researcher.
You replied that this would not be possible. You added that all of the children would have had contact with the medical team before and it would be made clear that female researcher would be conducting the interviews.

The Committee advised that the male: female interaction should be considered in the study findings.

- The Committee asked if [REDACTED] Hospital) have an irritable bowel nurse specialist.
You replied that there is an irritable bowel nurse specialist in the team.
- The Committee asked if the websites listed in the documentation are specific for children
You replied that 1 of the websites is for children the others are for adults.

The Committee stated that it should be made clear which websites are for adults and which are for children.

- The Committee stated that contact details of additional support should be added to the PIS.
You agreed to do this and added that [REDACTED] are able to offer Psychological support.
- The Committee asked why non English speakers would be excluded from the study.
You replied that important information would be lost in translation.
- The Committee asked if the GP would be informed.
You replied that all support would be offered through [REDACTED] Hospital.

The Committee agreed that there was no need to inform the GP.

Provisional opinion

The Committee would be content to give a favourable ethical opinion of the research, subject to receiving a complete response to the request for further information set out below.

The Committee delegated authority to confirm its final opinion on the application to a meeting of the sub-committee of the REC.

Further information or clarification required

1. Changes to the Participant Information Sheet (PIS):
 - a. Simplify the PIS for 12 year old children.
 - b. Clarify which websites are for adults and which are for children.
 - c. Add a statement to indicate that there will be an irritable bowel nurse available if needed.
 - d. Add a statement to indicate what the process will be if a participant becomes distressed.
2. Changes to the Consent Form (s):
 - a. Add a statement to consent to the use of anonymised quotes.
3. Consult the NRES website for advice on how to re-word the consent / assent forms and PIS's
(<http://nuhrise.org/wp-content/uploads/NRES-Guidance-on-Information-Sheets-and-Consent-Forms.pdf>).
4. Confirm that the male: female interaction and exclusion of non-English speakers will be considered in the study findings.

If you would find it helpful to discuss any of the matters raised above or seek further clarification from a member of the Committee, you are welcome to contact Stephanie Macpherson on 0117 342 1331.

When submitting your response to the Committee, please send revised documentation where appropriate underlining or otherwise highlighting the changes you have made and giving revised version numbers and dates.

If the committee has asked for clarification or changes to any answers given in the application form, please do not submit a revised copy of the application form; these can be addressed in a covering letter to the REC.

The Committee will confirm the final ethical opinion within a maximum of 60 days from the date of initial receipt of the application, excluding the time taken by you to respond fully to the above points. A response should be submitted by no later than 20 November 2012.

Membership of the Committee

The members of the Committee who were present at the meeting are listed on the attached sheet.

Statement of compliance

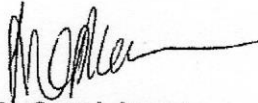
The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for

Research Ethics Committees in the UK.

12/LO/1112

Please quote this number on all correspondence

Yours sincerely



Ms Carol Jones

cc **Chair**

Email: ubh-tr.BromleyREC@nhs.net

Enclosures:

List of names and professions of members who were present at the meeting and those who submitted written comments.

Copy to:

Dr. Ken Gannon

Dr. [REDACTED]
[REDACTED]



Health Research Authority

NRES Committee London - Bromley

Bristol Research Ethics Committee Centre

Whitefriars

Level 3, Block B

Lewins Mead

Bristol

BS1 2NT

Telephone: 0117 342 1387

Facsimile: 0117 342 0445

20 August 2012

Miss Emma Micallef
Trainee Clinical Psychologist
Camden and Islington Mental Health NHS Trust
UEL, School of Psychology
Stratford Campus, Romford Road London
E15 4LZ

Dear Miss Micallef

Study title: Talking about an invisible illness: The Experience of
Young People with Inflammatory Bowel Disease
REC reference: 12/LO/1112
Protocol number: n/a

Thank you for your letter of 26 July 2012, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information was considered in correspondence by a sub-committee of the REC. A list of the sub-committee members is attached.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Ethical review of research sites

NHS sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

- 1) Changes to the participant information sheet (s):
 - a) Add the websites for young people with IBD (from the page of some helpful websites) to the young person information leaflet
 - b) Add the other IBD related websites (from the page of some helpful websites) to the parent/guardian information sheet
- 2) Changes to the Consent Form (s):
 - a) Add a statement to consent to audio recording.

You should notify the REC in writing once all conditions have been met (except for site approvals from host organisations) and provide copies of any revised documentation with updated version numbers. Confirmation should also be provided to host organisations together with relevant documentation.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at <http://www.rdforum.nhs.uk>.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of approvals from host organisations

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Covering Letter		19 June 2012
Evidence of insurance or indemnity		21 June 2012
Interview Schedules/Topic Guides	2	26 July 2012
Investigator CV		
Letter of invitation to participant	2	26 July 2012
Other: CV for academic supervisor		
Other: UEL requesting amendments to Registration Documents		26 January 2012
Other: Responding letter having made the amendments to the Registration Documents		05 February 2012
Other: Approval of Registration Document after Amendments to application forms		23 February 2012
Other: [REDACTED] Hospital's CRAC Team's requesting amendments to application form		23 February 2012

Other: Responding letter having made the amendments to CRAC application form for [REDACTED] Hospital		21 May 2012
Other: Additional Information Sheet	2	26 July 2012
Other: Confirmation of Ethical Approval from UEL		26 July 2012
Participant Consent Form: Assent Form for Young People	2	26 July 2012
Participant Consent Form: Consent Form for Parents/Guardians	2	26 July 2012
Participant Information Sheet: Young Person's Information Leaflet (i.e. Invitation Letter)	2	26 July 2012
Participant Information Sheet: Parent/Guardian Information Sheet	2	26 July 2012
Protocol	2	26 July 2012
REC application		
Response to Request for Further Information		26 July 2012

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Reporting requirements

The attached document "*After ethical review – guidance for researchers*" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

Feedback

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

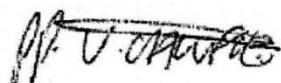
Further information is available at National Research Ethics Service website > After Review

12/LO/1112

Please quote this number on all correspondence

With the Committee's best wishes for the success of this project

Yours sincerely



Ms Carol Jones
Chair

Email: ubh-tr.BromleyREC@nhs.net

Enclosures:

List of names and professions of members who were present at the meeting

"After ethical review – guidance for researchers" [SL-AR2]

Copy to:

Dr. Ken Gannon

Dr. [REDACTED] Foundation

Trust [REDACTED]

NRES Committee London - Bromley

Bristol Research Ethics Committee Centre
Whitefriars
Level 3, Block B
Lewins Mead
Bristol
BS1 2NT

Telephone: 0117 342 1387
Facsimile: 0117 342 0445

31 August 2012

Miss Emma Micallef
Trainee Clinical Psychologist
Camden and Islington Mental Health NHS Trust
UEL, School of Psychology
Stratford Campus, Romford Road London
E15 4LZ

Dear Miss Micallef

Full title of study: Talking about an invisible illness: The Experience of Young People with Inflammatory Bowel Disease
REC reference number: 12/LO/1112
Protocol number: n/a
EudraCT number:

Thank you for your letter of 20 August 2012. I can confirm the REC has received the documents listed below as evidence of compliance with the approval conditions detailed in our letter dated 16 August 2012. Please note these documents are for information only and have not been reviewed by the committee.

Documents received

The documents received were as follows:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Covering Letter		20 August 2012
Participant Consent Form: Consent form for Parents/Guardians	3	20 August 2012
Participant Information Sheet: Young person's information leaflet (i.e. Invitation Letter)	3	20 August 2012
Participant Information Sheet: Parent/Guardian Information Sheet	3	20 August 2012

You should ensure that the sponsor has a copy of the final documentation for the study. It is the sponsor's responsibility to ensure that the documentation is made available to R&D offices at all participating sites.

12/LO/1112	Please quote this number on all correspondence
-------------------	---

Yours sincerely



Miss Vicky Canfield
Assistant Committee Co-ordinator
E-mail: ubh-tr.BromleyREC@nhs.net

Copy to: Dr. Ken Gannon,
Dr ~~Leslie Gibson~~, ~~_____~~ Hospital NHS Foundation Trust ~~_____~~
~~_____~~

Appendix 2- Ethical approvals

(c) Ethical approval from hospital's Clinical research adoption committee

[REDACTED]

[REDACTED]

[REDACTED] Great Ormond Street



Hospital for Children

NHS Trust

Joint Research and Development Office
Division of Research and Innovation

Attn: Dr Kate Rigby

23rd February 2012

Title: Talking about an invisible illness: The experience of Young People with inflammatory Bowel Disease (IBD)
R&D Ref: 12GA01
Funding: Clinical Own Application
Decision: Resubmission

Dear Kate

I am writing to inform you that the Clinical Research Adoptions Committee (CRAC) recently reviewed your application.

Whilst the Committee was generally supportive of your project, some issues arose that unfortunately prevented approval being granted at this stage.

The Committee had the following comments:

- The committee felt that the scientific justification for the study was not sufficiently argued. Could the applicants provide more information on why this particular group of children/this medical condition was chosen, and provide a clearer theoretical background for the study. How this study will add to existing knowledge in the field is not sufficiently explained.
- A stronger case/rational needs to be given for why the time of transition is being focussed on, especially as the young people are being asked to think back up to 3 years after they have moved to secondary school. Could the applicants state why they have chosen to specifically recruit 12-14 year olds.
- The proposal does not discuss the possible impact of the severity of the condition on the recruitment of participants, or the potential influence on the results. Given that the conditions can vary significantly in their severity and impact on daily functioning, the researchers should consider excluding children at the extreme ends of the spectrum.
- In terms of the methodology, please could the applicants provide information on the quality control methods they intend to use to ensure the validity and reliability of the findings.

Joint Research and Development Office
Division of Research and Innovation

[REDACTED]

[REDACTED]

[REDACTED]

[REDACTED]
[REDACTED]

[REDACTED]



Hospital for Children

NHS Trust

Joint Research and Development Office
Division of Research and Innovation

- The statement regarding dialling 999 etc. (Appendix 7) should be removed and replaced with more appropriate advice if support is required.

Therefore, I would be grateful if you would resubmit a revised proposal which addresses the committee's concerns. Details of future CRAC submission deadlines for 2012 are attached.

Yours sincerely

H B Gaspar
Chair
Clinical Research Adoption Committee

Encs

Joint Research and Development Office
Division of Research and Innovation

[REDACTED]
[REDACTED]
[REDACTED]

[REDACTED]

[REDACTED]
[REDACTED]

Attn: Dr Kate Rigby
Gastro

27/6/12

Dear Kate

Title: Talking about an invisible illness: The experience of Young People with inflammatory Bowel Disease (IBD)
R&D Ref: 12GA01
Funding: Clinical Own Account
Decision: Approved

I am writing to inform you that the Clinical Research Adoptions Committee (CRAC) reviewed your application and has no objections to the conduct of this project at [REDACTED].

The Committee did have the following recommendations:

- You have taken the comments made by this committee on board and made significant improvements to the proposal. For example the theoretical rationale for why this study is of interest and why study the period of transition to secondary school are much more clearly explained e.g. understanding of stigma and shame associated with embarrassing condition.
- Restricting to age 12 – some will reach age 12 soon after starting secondary whereas other will not be 12 until end of year 7. It was suggested that it would be better to select children in year 8 at secondary school.
- There is some lack of clarity around what is 'medium' severity of IBD and this needs to be made clearer in the proposal by defining what sort of conditions would be included and excluded.
- There are some inconsistencies in the submitted information (e.g. you need to change some of the recruitment information as it still says 12 -14) and there are some typos, so the proposal needs to be proof read to ensure consistency throughout.

[REDACTED]
[REDACTED]

Joint Research and Development Office
Division of Research and Innovation

You will shortly receive a checklist of documents that are required for R&D approval. Once all the documents have been received you will receive an R&D approval email and you can commence your project.

Regards



H B Gaspar
Chair
Clinical Research Adoption Committee

Joint Research and Development Office
Division of Research and Innovation

[REDACTED]
[REDACTED]
[REDACTED]

[REDACTED]

Appendix 2- Ethical approvals

(d) Local research at development team approval

[REDACTED]

[REDACTED]

[REDACTED] **NHS**

Hospital for Children

NHS Foundation Trust

Joint Research and Development Office
Division of Research and Innovation

Direct Line: 020 7905 2698

Email: Marice. [REDACTED]@ [REDACTED]nhs.uk

06/11/2012

Miss Emma Micallef
Trainee Clinical Psychologist
University of East London, School of Psychology
Stratford Campus
Romford Road, London

Dear Miss Emma Micallef

PROJECT TITLE	Talking about an invisible illness: The experience of young people with Inflammatory Bowel Disease (IBD)
Protocol version	Version 3
Protocol date	20.08.12
REC Reference	12/LO/1112
R&D Reference	12GA01
CSP Reference	
Sponsor	University of East London
Chief Investigator (CI)	Miss Emma Micallef

Notification of [REDACTED] Hospital NHS Permission.

The research approval process for the above named study has been completed successfully. I am pleased to issue approval on behalf of [REDACTED] Hospital for Children NHS Trust, [REDACTED] for the above study to proceed.

All research carried out within this Trust must be in accordance with the principles set out in the Research Governance Framework for Health and Social Care (April 2005, 2nd edition, Department of Health (DoH)).

This approval is issued on the basis of the project documentation submitted to date. The approval may be invalidated in the event that the terms and conditions of any research contract or agreement change significantly and while the new contract/agreement is negotiated.

The conditions for host site approval are as follows:

- The Principle Investigator (PI) must ensure compliance with protocol and advise the Joint R&D Office of any change(s) to the protocol. Failure of notification may affect host approval status.
- Under the terms of the Research Governance Framework (RGF), the PI is obliged to report any Serious Adverse Events (SAEs) to the Sponsor and the Joint R&D Office in line with the study

Joint Research and Development Office
Division of Research and Innovation

[REDACTED]

[REDACTED]

Page 1 of 2

Non-CTIMP approval V2.0

[REDACTED]
12GA01

protocol and Sponsor requirements. Adverse Incidents (AEs) must also be reported in accordance with the Trust Adverse Incident Reporting Policy & Procedures.

- The PI must ensure appropriate procedures are in place to action urgent safety measures.
- The PI is responsible for the set up and maintenance of the Investigator Site File (ISF) generated to store all documentation relating to this project.
- The PI must ensure that all named staff are compliant with the Data Protection Act (DPA) 1998, Human Tissue Act (HTA) 2005, Mental Capacity Act (MCA) 2005 and all other applicable statutory guidance and legislation.
- The PI must allow monitoring and auditing by the Sponsor and the Joint R&D Office.
- The PI must report any cases of suspected research misconduct and fraud to the Joint R&D Office.
- The PI must provide an annual report to the Joint R&D Office for all research involving NHS patients, staff and/or resources. The PI must notify the Joint R&D Office of any presentations of such research at scientific or professional meetings, or on the event of papers being published and any direct or indirect impacts on patient care.


Failure to comply with the above conditions and regulations will result in the suspension of the research project.

Please contact the Joint R&D Office if you require any further guidance or information on any matter mentioned above. We wish you every success in your research.

Yours sincerely,



Marice Lunny
Senior Research Governance Manager
Joint Research and Development Office

cc: Dr Kate Rigby, 
Dr Ken Gannon, UEL

Appendix 3 – Invitation letter



Emma Micallef
School of Psychology
Doctorate in Clinical
Psychology Office
University of East London
Stratford Campus
Water Lane, London
E15 4LZ

Date: _____

Dear *(young person)* and *(parent)*,

RE: Telling others about having Inflammatory Bowel Disease (IBD) Research Project

Thank you for showing interest in this research project.

I have attached some information for you to read about the research project. Inside this letter you will find:

- **Two Information leaflets- one for parents/guardians, another for young people:** This will tell you more about the research, what you will be asked to do if you take part, information about confidentiality and a list of sources of support and advice.
- **Consent and Assent forms:** If you choose to take part you will be asked to sign these consent form before the interview begins.

If you would like to take part in this research or if you have any questions about the information inside this letter please contact by e-mail or telephone:

E-mail: u1037635@uel.ac.uk

Telephone : 020 8223 4174/4567 (University of East London, Doctorate in Clinical Psychology office)

Many thanks in advance.

Best Wishes,

Emma Micallef
Trainee Clinical Psychologist
University of East London

Appendix 4- Parent information sheet

Study title: Talking about an invisible illness: The Experience of Young People with Inflammatory Bowel Disease

Invitation to participate in the study

Your child with Inflammatory Bowel Disease (Crohn's disease or ulcerative colitis) and you, as their parents/guardians, are being invited to take part in this research study. Before you decide whether or not to take part, you need to understand more about why the research is being done and what it would involve for you and your child. Please take time to read the following information carefully.

Explanation of title of study:

Talking to others about having Inflammatory Bowel Disease (IBD), an illness that is not readily visible to others, can be a difficult experience to manage. This may be particularly so for young people who are starting secondary school. The purpose of this study is to discover what it is like as a young person with IBD, having moved from primary to secondary school, to tell others that they have Crohn's disease or ulcerative colitis.

Ethics Approval

This study has been approved by two independent Local Research Ethics Committees.

What is the purpose of this study?

Research carried out in adults with less visible health conditions (like diabetes, HIV and cancer) have shown that choosing to talk to other people about having such illnesses can be difficult to manage. Relatively little research exists on how young people with such conditions manage this experience.

What we would like to do is to improve our knowledge of how young people with IBD choose to talk or not to talk to others about their condition and how they manage this experience, particularly around the time they move into secondary school. We will consider how young people choose who they do and do not want to tell, how young people choose how much to tell them, and what helps and hinders them when talking about IBD.

Why has your child with IBD been chosen?

Your child has been chosen because they have a diagnosis of Crohn's Disease or Ulcerative Colitis- two types of an illness sometimes called Inflammatory Bowel Disease. We are looking for 6-8 young people who have IBD, and who are in Year 8 at and have transitioned from primary to secondary school with the condition to help us in this study.

Do I have to allow my child to participate in the study?

No, your child does not have to participate in the study. If you do allow your child to take part, you will be given a consent form that needs to be signed prior to starting the study. You are still free to withdraw your child from this study at any time after signing consent without giving a reason. A decision to withdraw or not to take part, will not affect the standard of care your child receives.

What does the study entail for your child?

Your child will be asked to take part in an interview with a female researcher. During the interview your child will be asked questions about what it has been like to talk to others about their IBD, having moved to secondary school. The interview will only happen once and will last for up to one hour, but could be shorter.

This interview will take place at _____ Hospital on a date and time that suits you and your child best. To save you coming in to the hospital more than you need to, the interview can take place before or after one of your child's scheduled outpatient appointments at the hospital. Once we have our findings we will notify you with our results.

What are the benefits/disadvantages to this study?

The study will help us to better understand the experience of young people with IBD and how they manage talking to others about their condition, one that is less visible to others. This will improve the way we and other professionals (e.g. doctors, nurses, psychologists, teachers) work with other young people with IBD. By identifying some of their concerns, this information will also be used to develop effective and targeted support for such young people. Whilst most of the benefits of this research are likely to accrue to future young service users, the young people who take part may benefit indirectly. They may find talking to someone removed from their clinical care, particularly about issues that may not be discussed in their normal clinical appointments, to be a positive and rewarding experience.

For a few people find talking about certain experiences can remind them of sad or difficult times in their life. If any of the young people taking part in the research start to feel distressed the researcher will remind them that are able to stop taking part in the study at any time. During the interview the researcher will use her specialist psychology experience to ensure that young people are comfortable and able to carry out the interview. Following the interview, if the researcher feels that additional support may be beneficial, participants will be put in touch with one of the IBD nurses at _____ Hospital. If appropriate, a referral for local or _____ Hospital psychological support can also be facilitated.

Who will have access to your child's medical records for this study?

The researcher will not access your child's medical records.

What will be done with the information of the study?

The findings will be published in a medical and/or psychology journal, so that other professionals will be able to adapt their practice according to our results. No personally identifiable information will be published. All participant quotes used in publications will be anonymised.

Will I be informed regarding the result of the study?

All families will be asked if they wish to be sent an executive summary of the results and the initial implications.

Will my child's information be kept confidential?

All information will be anonymised, which means that your child's hospital number will not be used in this study, as they will be allocated a unique study number once they

have been enrolled. All data used in any future publications, including the use of participant quotes, will be entirely anonymous and no identifying details will be included in any publication of this research. Any information collected in this study will be stored on a secured network drive that is encrypted.

Who is organising this study?

This research project will form part of the researcher's Professional Doctorate degree in Clinical Psychology at the University of East London as part of. It is taking place under the supervision of Dr _____, Clinical Psychologist, Dr _____, Consultant Paediatric Gastroenterologist, and Dr Kenneth Gannon, Clinical Research Director on the Doctorate in Clinical Psychology programme at University of East London.

Will my GP be informed?

Your child's gastroenterologist at _____ Hospital will be informed of their participation in the study. Your child's GP will not be informed.

Who do I contact if I have a complaint OR would like to discuss any issues?

This study is covered under the University of East London's Indemnity scheme, although there are no special compensation arrangements.

If you have any questions, concerns or complaint's please contact Emma Micallef (Trainee Clinical Psychologist) on:

E-mail: u1037635@uel.ac.uk

Telephone (University of East London, Doctorate in Clinical Psychology office): **020 8223 4174/4567**

Thank you for taking your time to read this information sheet and we look forward to meeting you.

Some Helpful Websites:

IBD related Websites (containing information for people of all ages):

Website for The National Association for Colitis and Crohn's Disease (NACC)- IBD charity that brings together people of all ages who have been diagnosed with IBD, their families and the health professionals involved in their care: www.crohnsandcolitis.org.uk



Website for Crohn's Zone- Crohn's Zone is a friendly interactive forum based community for people all over the world with Crohn's disease and ulcerative colitis: www.crohnszone.org



What is it like as a young person to tell others that you have Crohn's or Colitis?



Hello! We are a research team based at ____ Hospital and you are being asked to help us with a new project we are researching. This sheet tells you all about the project and you can read it with your parent or the person taking care of you or you can read it on your own.

If you have any questions that your mum, dad or the person taking care of you cannot answer, then the best people to talk to are the research team. Their names are **Emma** or **Kate**. You can call us on: (*University of East London, Doctorate in Clinical Psychology office*): **020 8223 4174/4567** and there is also an email address to contact us on which is u1037635@uel.ac.uk. We will be happy to answer any questions you may have.

What is the project about?

We know that you have got a type of Inflammatory Bowel Disease (sometimes called IBD; either Crohn's disease or ulcerative colitis). This means that your immune system isn't working right, and it makes your stomach and intestines get red and sore inside. This makes most people's stomachs hurt and gives them diarrhoea, which means spending a lot of time in the toilet.



We also know that over the last year you have moved from primary school to secondary school. Now that you are in secondary school we would like your help in finding out what it is was like talking to other people about having IBD, Who you did and didn't tell in secondary school, how you decided to tell them, what you told them and what helped you to tell these people about your IBD.

Why are we doing this research?

The purpose of the project is to find out what it is like as a young person with IBD, having moved from primary to secondary school, to tell others that they have Crohn's or colitis.

Why have I been invited to take part?



You have been asked to take part because you are in year 8 at school AND because you have Crohn's Disease or Ulcerative Colitis- two types of an illness sometimes called Inflammatory Bowel Disease (IBD). We are looking for 6- 8 young people who are in year 8 and have IBD to help us in this study.

Do I have to take part?

No, you do not have to do anything you do not want to do. It is your choice. If you decide that you do not want to take part, your treatment at ____ will not be affected.

What do I have to do if I want to take part?

You will take part in an interview with a female researcher. The interview will only happen once. It will last for up to one hour but could be shorter. This interview will take place at ____ Hospital on a date and time that is best for you. We can even have the interview before or after an appointment you have with the doctors or nurses at ____ Hospital, to save you coming in to the hospital more than you need to.



During the interview I will ask you questions about what it has been like to talk to others about your IBD, having moved to secondary school. This will last no longer than an hour. I will use a tape recorder when I talk to you so I can remember what you said. After the interview I will use the recording of the interview to type out what we talked about.

How will my taking part be kept confidential?

The only people who will know are you, your parents/guardian and your doctor. I will **ONLY** tell another adult what you have said in the interview if I believe that you or someone else might not be safe. Otherwise, all of your information will be kept a secret. Your name and hospital number along with other identifying data will be removed from all the documents we need. When I have finished my project I will write it into a report. Any information that might tell others who you are will be removed or changed in the report to make sure your identity remains a secret from anyone else.

Is there anything to be worried about if I take part?



A few people find talking about certain experiences can make them feel sad or scared. If you feel this way we will not push you into doing anything you don't want to. You can stop taking part in the research

If you are worried about how you are feeling after you have taken part in the research, you can speak to your IBD Nurse at ____ Hospital about this. I can also help you get in touch with the IBD nurses or other sources of advice if you feel you need some further support.

What could be the good things about taking part?

Some people find talking to other people about their past experiences helpful. One of the main benefits for the future will be to other children who are diagnosed with the same condition as you. The information we get will help us and other people to get a good understanding of what it is like as a young person to tell others that they have Crohn's or Colitis. This could help people working with other young people with IBD (like doctors, nurses, psychologists, teachers) to find new and maybe better ways of working with these young people in the future.



Has anyone else checked that this project is safe to do?

Yes, all research projects have to be cleared by a group called the Research Ethics Committee. It is their job to keep you and other children and young people safe if you are participating in research.

If you have any questions, please call us on the above number and we will be happy to talk to you at any time.

Some Helpful Websites for Young People with IBD

- UC and Crohn's site for teens – site offering teens practical advice on handling their illness, facts on nutrition, school survival tips and more: www.ucandcrohns.org



- Children with Crohn's and Colitis website: www.cicra.org



- Growing Up IBD website - Dedicated to raising awareness about Inflammatory Bowel Disease : www.growingupibd.org



Appendix 6- Consent form for parents



Consent Form for Parents/ Guardians

Title of Project: **Talking about an invisible illness: The Experience of Young People with Inflammatory Bowel Disease**

Name of Researcher: **Emma Micallef (Trainee Clinical Psychologist)**

Patient Identification

Number for research: _____

Please initial box:

1. I confirm that I and my child have read and understand the information sheet dated (version.....) for the above study. We have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐
2. I understand that my child's participation is voluntary and that my child is free to withdraw from the study at any time without giving any reason, without my child's medical care or legal rights being affected. ☐
3. I understand that data collected during the study may be looked at by the researcher and their supervisors, one from the University of East London and the other from _____ Hospital. I give permission for these individuals to have access the data collected during my child's interview. ☐
4. I agree to the audio recording of the interview. ☐
5. I agree to the use of anonymised quotes in publications. ☐
6. I agree to my child's consultant and IBD Nurse being informed of their participation in this study. ☐
7. I agree to my child taking part in the above study. ☐

Name of Parent

Child's name

Date

Signature

Appendix 7- Assent form for young people



Project title: Talking about an Invisible Illness

Young person to circle all they agree with:

Has somebody else explained this project to you?	Yes/No
Do you understand what this project is about?	Yes/No
Have you asked all the questions you want?	Yes/No
Have you had your questions answered in a way you understand?	Yes/No
Do you understand it's OK to stop taking part at any time?	Yes/No
Are you happy to take part?	Yes/No

If any answers are 'no' or you don't want to take part, **don't sign your name!**

If you do want to take part, you can **write your name below**

Your name: _____

Date: _____

The professional who explained this project to you needs to sign too:

Print Name: _____

Profession: _____

Sign: _____

Date: _____

Thank you for your help!

Appendix 8 - Interview schedule

Prior to the interview:

- a. Make introductions with both the young person and their carer.
- b. Ask if they have read relevant information sheets and if they have any further questions
- c. Give an idea of what to expect from the interview (i.e. how long the interview might go on for, letting them know that at any point during the interview they may take a break).
- d. Ask young person and their carer to read and sign the appropriate consent and assent forms.
- e. Explain:
 - asking lots of questions, sometimes the same question in different ways, some might sound silly
 - no right or wrong answer – just want to capture your experiences
 - I will be checking words and meanings out to make sure I know what you mean - to avoid assuming that I know what you mean
 - If any images, metaphors come to mind when you are talking to me I would be really interested in hearing these. If you have any stories or examples that come to mind when I ask your questions, and you wouldn't mind sharing these, these would be great to hear.

- **Introductory questions:**

- What year at school are they at?
- How are they finding secondary school?
- What do they most enjoy at school?
- What kind of IBD they have?

- **Talking to others (PEERS and STAFF) about IBD:**

- Who, if anyone, did you tell in secondary school that you had IBD?
- Can you tell me about a time in secondary school when you chose TO TELL someone you had IBD?

Prompts:

- How did you decide to talk to them about it? -> ask for examples
- What did you tell them?
- How did you feel after you told them?
- How did they act after you told them?
- What has it been like to talk to your FRIENDS/PEERS about your IBD since moving into secondary school?

- What's it been like talking to STAFF about it in secondary school?
- What changes, if any, have you noticed in the way you talk about IBD since moving from primary to secondary school?
- How do you think things would be different if you HADN'T told them about your IBD?

- **Not talking to others (PEERS and STAFF) about IBD:**

- Can you tell me about a time in secondary school when you chose NOT to tell someone you had IBD?

Prompts:

- How did this make you feel?
- What did you do next?

- How do you think things would be different if you HAD told them about your IBD?

Prompts:

- Would you have felt differently?
- Would they have acted differently?

- **What helps/hinders talking about IBD:**

- What, if anything, helped you to talk about your IBD?
- What, if anything, made it more difficult for you to talk about your IBD?

- **Help in Telling others:**

- Can you tell me what help, if any, you had in letting other people know about your condition?

Prompts:

- Who helped you? -> What was that like?
- Would you have preferred to tell others about your IBD yourself more than you did?
- Less than you did?

- **Closing Questions:**
 - Is there **anything else** you that is important for me to know about to **understand your experience**?
 - **Any questions I didn't ask you that you thought I might ask?**
 - **How has it been talking with me today?**
-

At the end of the interview:

- Give Further information sheet
- Ask parent and young person if they would like to receive an executive summary of the results when the study is completed
- Thank them for their time

**Appendix 9- Audit trail: Sample of analysed transcript
(Interview 2 – Tyler)**

<p>Forced to tell teachers to prevent embarrassing situation (ie. having accident) (necessity = foundation to telling teachers)</p> <p>Trust is the foundation for telling peers (170-171)</p> <p>Having to explain condition to friends (174-179)</p> <p>Having to explain condition to friends (182-184)</p> <p>Purposefully choosing not to name illness to friends - to protect from teasing (retaining control about increased toilet use)</p>	<p>152 I: And, can you give me an example of a time 153 when you did talk to someone in primary school? 154 Tyler: Well, as soon as I got back from X hospital, 155 erm, my mum had to go to school and tell all my 156 teachers about what I had and erm, about a 157 week later I had to really go [toilet] and I had a 158 really bad bellyache so I ran to the toilet. Then I 159 got sent home because it was quite bad still, like 160 a week after I found out I had it. 161 I: So you said you had to run to the toilets and go 162 there. How have things been for you now in 163 secondary school? 164 Tyler: I've had a flare-up and was in hospital for a 165 bit. But the medicine is working now I think. 166 I: So things are Okay at the moment? 167 Tyler: Yeah. 168 I: Who, if anyone, did you tell in secondary 169 school that you have colitis? 170 Tyler: Erm, I told all my best mates that I know 171 and that I trust. 172 I: Can you tell me about other time when you told 173 them? 174 Tyler: Erm, when I got back from hospital they 175 said, "Why do you keep going back to hospital 176 again" and I said, "Well, I have like, something in 177 my stomach, yeah, and that keeps making me go 178 to the toilet. That's why I kept going to hospital. 179 And I get really bad bellyaches". 180 I: Did they ask you any questions after that? Or 181 what kinds of things that they ask? 182 Tyler: They just asked, "Is it painful" and stuff and 183 I said, "Sometimes, depending on if I have a flare 184 up". 185 I: Did you, you said that your bellyaches and that 186 you have to go to the toilet a lot and, erm, I was 187 wondering, did you give them the name of your 188 illness? 189 Tyler: No, I didn't give them the name (smiles). 190 I: Could you say a bit more about that, about not 191 saying the name? 192 Tyler: Erm, I was trying to think of the name then 193 but I couldn't quite remember it. I know it began 194 with like a 'K' but I couldn't think of it. 195 I: What was the thinking behind not saying more? 196 Tyler: Erm, just in case they would laugh or 197 something like that. 198 I: You said just in case they would laugh. Can 199 you say a bit more about that? 200 Tyler: Erm, like coz it's not normal going to the 201 toilet that much, so I thought that, erm, they 202 would take the mick out of me. 203 I: Okay, so can you say a bit more about that?</p>	<p>use of word 'had' indicates lack of choice his mum had in telling teacher</p> <p>Symptoms required immediate action ie running to the toilet. No time to talk.</p> <p>being sent home for school a week after diagnosed because he was having a bad flare</p> <p>feeling like he doesn't have IBD anymore at secondary school because meds are working.</p> <p>telling all his best mates who he knows he can trust</p> <p>being asked on return to school from hospital about frequent hospital visits.</p> <p>telling friends that he kept going to hospital because of stomach problems + that stomach problems kept making him go to the toilet.</p> <p>talks about diarrhea indirectly</p> <p>answering questions about pain. Uses term flare-up (associated with IBD)</p> <p>not giving friends name of condition</p> <p>unable to remember condition's name. Not wanting to remember.</p> <p>Not saying more for fear of being laughed at.</p> <p>Fear of being made fun of because symptoms of IBD (diarrhea) made him different/not normal</p>
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<p>Relating toilet use to health condition limits potential teasing (204-210)</p> <p>Forced to talk about toilet use to prevent more harmful assumptions/teasing [fear of greater stigmatisation] (223-228)</p>	<p>204 205 206 207 208 209 210 211 212 213 214 215 216 217 218 219 220 221 222 223 224 225 226 227 228 229 230 231 232 233 234 235 236 237 238 239 240 241 242 243 244 245 246 247 248 249 250 251 252 253 254 255 256</p>	<p>Tyler: Like, erm, if like, usually like, if you are normal, you wouldn't go to the toilet as much but if like I kept going to the toilet, they would think something was really [emphasis on word in the really] wrong with me so I thought that they would then, like <u>keep taking</u> the Mickey out of me and stuff. <u>↳ repeated teasing?</u></p> <p>I: So you thought they'd take the Mickey out of you if you did have to go to the toilet a lot and they noticed that?</p> <p>Tyler: Yeah.</p> <p>I: So is that when you decided to tell them that you had something wrong?</p> <p>Tyler: Yes.</p> <p>I: Okay. And you said when you told... I'm interested in what was going through your mind when you were thinking about going to the toilet and if it did happen that that you did go to the toilet and they might take the mickey out of you.</p> <p>Tyler: I was erm. I can't really erm, I don't really want to tell them, but like, I just want, I just told them so they know and they didn't take the mickey out of me. Because, if I didn't tell them they would actually think that there's something wrong, but then I told them <u>what was wrong</u>.</p> <p>I: When you say they think something is wrong, what you mean by the word wrong?</p> <p>Tyler: Like, erm, I can't quite explain. But erm <u>[pause]</u> I think like something inside me, but then I told them what was actually proper wrong, so they don't think it's something else.</p> <p>I: So you said, so that they don't think it's something else. What did you think they might think it was? What could the something else be?</p> <p>Tyler: I don't know, like I'd eaten something dodgy or something like that and take the mickey.</p> <p>I: I noticed you said the words, "Proper wrong" earlier, what does 'proper wrong' mean?</p> <p>Tyler: Erm, <u>[pause]</u> like, I can't explain it. Erm, like, Because, this is not, this just ain't normal, but like erm if there was something that I didn't know of like... I can't quite explain it. <u>[pause]</u> mmmm. No, I can't explain it.</p> <p>I: Could you maybe give me an example to explain it, would that help? Or maybe an image or a picture?</p> <p>Tyler: Like, being sick a lot and something like that. I told them like, that there was something <u>inside of me that kept making me go to the toilet and they understood that.</u> <u>↳ health condition - couldn't be helped(?)</u></p> <p>I: So you said that there is something inside of you that makes you keep going to the toilet?</p> <p>Tyler: Yeah.</p>	<p>↳ Not feeling normal</p> <p>↳ Going to the toilet means you are not normal + that something is really wrong.</p> <p>↳ fear that people will tease him if they know thought something was really wrong.</p> <p>↳ Not really wanting to tell them.</p> <p>↳ Telling so they wouldn't tease him</p> <p>↳ Fear of friends thinking diagnosis was worse than it actually was</p> <p>↳ Telling them about IBD</p> <div data-bbox="1193 1010 1385 1182"> <p>Telling them he has colitis is safer than them thinking he has diarrhoea or goes to the toilet a lot</p> </div> <p>↳ Telling them talking about a legitimate condition is safer than just having diarrhea.</p> <p>↳ IBD is externalised</p> <p>↳ Having IBD is not normal. ↳ makes him different.</p> <p>↳ friends understanding that something inside him made him go to the toilet.</p> <p>↳ friends understanding that illness is beyond his control.</p> <p>↳ didn't tease him</p>
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Felt condition was taken seriously + seen as illness. (258-260)

Waiting for friends reactions.

Feeling accepted as Tyler with IBD by friends.

Waiting in anticipation to be accepted or rejected. (262-264)

Talking about IBD with the embarrassing not may lead to rejection for peers (with peers) 273-278

Having a Medical diagnosis protects against embarrassment associated with symptoms

normalising increased toilet use.

Having medical condition normalises his exps for peers (281-285)

(Preventive disclosure): Friends increased understanding about IBD prevents teasing peers

Increased understanding prevents teasing (295-300)

Having a legitimate reason for increased toilet use

Relating toilet use to medical condition protects from other more harmful assumptions (303-306)

257 I: How did you feel when you did tell them?
258 Tyler: I thought they were going to take the
259 Mickey out of me, but then they took it seriously.
260 So I felt alright then.
261 I: did you feel all right straightaway?
262 Tyler: No, because they didn't really say anything
263 straightaway. But, as soon as they said, "Ahh
264 that don't matter" then I felt happier a bit.
265 I: How long did it take for them to, for you to feel
266 alright?
267 Tyler: Probably about five seconds, something
268 like that
269 I: So not very long?
270 Tyler: yeah
271 I: And when you say alright, can you describe
272 that to me? What does alright look like for you?
273 Tyler: I thought I was going to be embarrassed in
274 front of them, so I thought they'd go around
275 telling everyone but they, like when I told them,
76 they said, "That's alright" and then they just kept
77 it a secret. So, they, they are just as normal
78 around me.
79 I: And when you say normal, what does that
mean to you?
280 Tyler: Erm, because like, if they normally go to
281 the toilet regularly erm, because I have
282 something inside of me, they would understand
283 that. It's like my normal routine of going to the
284 toilet.
285 I: So they'd know that that's part of the routine for
286 you.
287 Tyler: Yes.
288 I: So, you wanted them to know you had
289 something inside of you and that it was your
290 normal routine. What was that like telling them?
291 Tyler: What do you mean?
292 I: Could you, maybe, say a bit more about telling
293 these friends?
294 Tyler: Erm, because if I didn't tell them they
295 would just probably take the Mick out of me as I
296 keep going to the toilet and stuff like that. But if I
297 told them, like why I kept going to the toilet, they
298 would understand and why I kept going to the
299 toilet a lot.
300 I: You said they would understand, what does the
301 word 'understand' mean for you?
302 Tyler: Because, if I didn't tell them and I kept
303 going to the toilet, they wouldn't really know why I
304 kept going to the toilet, but I told them why so
305 they know why I keep going to the toilet.
306

medical conditions = serious friends saw it as illness.

Taking seriously + not teasing him.

Silence after initial disclosure (to friends) felt not alright

Feeling happier after friends said IBD diagnosis didn't matter.

Speculation of abuse Fear of feeling embarrassed whilst talk to friends.

Fear of spreading news of IBD.

Feeling accepted around by friend + protected (from sharing secret)

Friends understand that going to toilet is normal for him + out of his control going 2 toilet is due to medical reasons.

Telling friends & they understand increased toilet use + won't tease him about it.

Wanting them to know the real reason why he went to the toilet

IBD being medical condition makes it m. legitimate protects from teasing.

<p>(315-319) Trusting friends to keep his secret reason did not want to tell as it could lead 2 teasing</p> <p>Wanting info. given to friends to remain a secret + not common knowledge (control of stigma?) (325-329).</p> <p>Feeling that secret is safe with friends (331-334)</p>	<p>307 I: And before we're talking you said you had 308 some worries that there were those five seconds 309 where you sort of didn't know what they were 310 going to say and I think you mentioned that that 311 you were worried about them telling other people 312 can you talk to me a bit more about that? 313 Tyler: Erm, like if I, if they did go around telling 314 everyone, like everyone who I didn't know would 315 start to taking the mick out of me, but because I 316 trust them, erm I told just them, I told them to 317 keep it a secret. Then, after like five seconds 318 they said, "Alright, I promise I won't tell anyone" 319 and they've told no one since. 320 I: How many friends did you tell? 321 Tyler: About two or three, and that's it. But they 322 are my three best friends 323 I: What's that like, to use your own words, having 324 a secret or carrying that secret around at school? 325 Tyler: Because I wanted to keep it a secret so 326 that no one else knows, but my best friends 327 whom I trust because if they told other people 328 who I don't really trust they might turn everyone 329 in the school. get people to change their opinion of him 330 I: What is it like to live with that secret? 331 Tyler: It's alright, because I know that I trust them 332 and they won't really tell anyone else because 333 I've known them for a long time, since I've started 334 school.</p>	<p>→ Fear that people ^{who} doesn't know ^{if} might be told. + that he might be teased.</p> <p>→ trusting friends with secret. → asking friend to keep it a secret → friends honouring promise to keep it a secret.</p> <p>→ Telling only his best friends.</p> <p>→ Only telling people who he trusts</p> <p>→ Protecting self-image identity at school → Maintain privacy.</p> <p>→ feeling that secret is safe because he trusts friends.</p>
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**Appendix 10 – Audit trail: Emerging themes in chronological order
(Interview 2 - Tyler)**

Emerging Themes	Line Number
Feeling like he restarted school when he started secondary school	23-27
Not knowing what was going on when initially diagnosed	57-61
Scary being at school and not knowing what's wrong	113-114
Limiting disclosure when asked about illness related absences	135-136
Telling teachers collaboratively with mum	146-147
Telling teachers protects from potential embarrassment (i.e. potential accidents)	149-151
Forced to tell teachers to prevent embarrassing situation (i.e. potential accidents)	155-160
Trust is the foundation for telling peers	170-171
Having to explain condition and embarrassing symptoms to friends	174-179; 182-184
Purposefully choosing not to name illness to friends – to protect from teasing about increased toilet use	187-197; 200-202
Forced to talk about toilet use to prevent more harmful assumptions/ teasing (Fear of greater stigmatisation)	223-228
Relating toilet use to health condition limits potential teasing more harmful assumptions (socially threatening – teasing / stigma)	204-210; 231-234; 238-239; 303-306
Wanting friends to understand that illness makes him go to the toilet	251-253
Condition taken seriously by friends and seen as illness	258-260
Waiting in anticipation to be accepted or rejected by friends he had told	262-264
Talking about IBD is embarrassing and may lead to rejection from peers	273-278
Having a medical diagnosis protects against embarrassment associated with symptoms	281-285
Having a medical diagnosis normalises his experiences to peers	281-285
Peers increased understanding prevents teasing	295-301
Trusting friends to keep toilet use a secret – as could lead to teasing	313-319
Wanting information given to friends to remain a secret and not common knowledge	325-329
Feeling that secret is safe with friends	331-334

Feeling genuinely cared for by friends who knew (emotionally)	368-372; 384-386; 397-401
Feeling genuinely cared for by friends who knew (physically)	374-377 & 380-381
Living in fear of being exposed by peers who know	411-416; 434-438
Genuine concern from peers is only attainable through telling	421-427
Being exposed as having IBD would be embarrassing	445-447
Fearful of embarrassing info being spread	450-454
Helpful talking to peers who have IBD too	474-477; 480-487
Feeling understood/ less isolated	503-507; 528-529; 541-538
Talking to reduce isolation of self & others	534-538
Talking to peers who have IBD = sense of belonging	557-564; 597-602; 625-628
Not feeling alone	597-599
Wanting to maintain a sense of privacy but this = difficult	608-610
Embarrassing to talk about things that aren't regular (i.e. normal)	618-619
Having to manage peer curiosity	646-652
Forced to tell because of repeated hospital appointments (talking out of sense of necessity)	655-660
Easier to talk about procedures/ treatment rather than symptoms (less stigmatising/ more normal)	664-669
Feeling less alone/understood by peers who had similar procedures	676-678; 682-687
Easier to talk about colonoscopy than IBD itself	693-695
Talking about IBD beforehand facilitates discussions about procedure e.g. colonoscopy	698-703
Easier talking to people about tangible things like procedures	709-718
Harder talking about IBD which is inside him/less visible	721-725
Relief that teachers all know/have been told	750-755
Mum talking to teachers on his behalf and their knowing was helpful	757-761
Support from mum to talk to teachers is helpful	768-771
Having toilet pass initiates/ facilitates conversations with staff who don't already know	774-777
Telling teachers out of necessity – to avoid accidents	780-784
Easier talking to teachers as they have duty to understand	786-788
Safer talking to teachers rather than peers as they will not joke about it	794-796
Sharing responsibility to talk to teachers with mum is helpful	799-807

Talking is made easier by mum 'lending him the words' [scaffolding]	818-820
Mum sensitive to his desire to protect information [parents as protectors]	830-833
Mum talking to teachers bridges gaps in his knowledge of IBD	822-825; 833-838
Feeling more knowledgeable and accepting of diagnosis following transition to secondary school	845-847
Fear of being teased about IBD in secondary school prior to transition	904-909
IBD related conversations with teachers are taken seriously	985-990
Telling teachers protects him from potential teasing	998-1002
Logistics of secondary school (i.e. more teachers) makes prospect of talking to teachers harder	1008-1011; 1013-1016
Telling teachers prevents accidents and embarrassment at school	975-980; 1027-1032
Telling peers to protection against teasing and manages peer curiosity	1033-1038
Fear that people might use what he has told them against him	1054-1058; 1067-1069; 1072-1075
Fear of peers (he doesn't know well) not understanding increased toilet use [Fear of potential stigmatisation]	1092-1095
Easier to talk to peers who understand him and his illness	1117-1119
Contemplated preparing for move to secondary by telling peers in primary about his IBD	1174-1178
Easier telling people in secondary school than he'd thought prior to transition - because there are others with IBD in his school	1229-1234
Fear of being out of control of information	1237-1239
Feeling more comfortable with illness leads to wanting to increase understanding of IBD amongst others	1239-1243
Supported by mum to help teachers understand	1251-1253
Knowing more makes it easier to talk about IBD in secondary school	1258-1259; 1262-1263
Freedom from worry of forced disclosure	1272-1275; 1279-1281
Feeling less isolated by talking together (i.e. with others at school who have IBD)	1309-1311; 1314-1317; 1323-1325
Telling people is liberating	1327-1330; 1333-1336; 1339-1340; 1355-1357
Feeling comforted and supported after telling	1346-1348
True identity begins to be revealed through talking with peers	1375-1378

Appendix 11 - Audit Trail: Clustered themes and superordinate themes (Interview 2 - Tyler)

Stigma Management			
Emerging Themes	Line Number	Sub themes	Quotes
Forced to talk about toilet use to prevent more harmful assumptions/ teasing (Fear of greater stigmatisation)	223-228	Full disclosure to prevent more stigmatising assumptions – linking symptoms to medical condition	“I told them [close friends] what was actually proper wrong, so they don't think it's something else. [...] I don't know, like I'd eaten something dodgy or something like that and take the mickey.” (231-234; 238-239)
Relating toilet use to health condition limits potential teasing more harmful assumptions (socially threatening – teasing / stigma)	204-210; 231-234; 238-239; 303-306		
Wanting friends to understand that illness makes him go to the toilet	251-253		
Condition taken seriously by friends and seen as illness	258-260		
Having a medical diagnosis protects against embarrassment associated with symptoms	281-285		
Having a medical diagnosis normalises his experiences to peers	281-285		
Peers increased understanding prevents teasing	295-301	Giving limited information to	Erm, when I got back from hospital they said, “Why do you keep going back to hospital again” and I said,
Having to explain condition and embarrassing symptoms to friends	174-179; 182-184		

Limiting disclosure when asked about illness related absences	135-136	peers to protect from stigmatisation and satisfy peer curiosity	“Well, I have like, something in my stomach, yeah, and that keeps making me go to the toilet. That’s why I kept going to hospital. And I get really bad bellyaches”. (174-179)
Having to manage peer curiosity	646-652		
Telling peers to protection against teasing and manages peer curiosity	1033-1038	Less stigmatising to talk about procedures/ treatment rather than symptoms (more normal)	[...] Everyone can have an injection and stuff like that, but because the colitis is a part of me, erm, because it's just telling someone about [...] a part of you [...], it's easier telling people like what I have to have done.” (709-718)
Easier to talk about colonoscopy than IBD itself	693-695		
Talking about IBD beforehand facilitates discussions about procedure e.g. colonoscopy	698-703		
Easier talking to people about tangible things like procedures	709-718		
Harder talking about IBD which is inside him/less visible	721-725		
Waiting in anticipation to be accepted or rejected by friends he had told	262-264	Fear of teasing and peer rejection	I wanted to keep it a secret so that no one else knows, except my best friends whom I trust. Because, if [other peers] told other people who I don't really trust, they might turn everyone in the school. (325-329) [...] If they did go around telling everyone, like everyone who I didn't know would start to taking the Mick out of me, but because I trust them, [...] I told them to keep it a secret. Then, after like five seconds they said, “Alright, I promise I won't tell anyone” and they've told no one since. (313-319)
Talking about IBD is embarrassing and may lead to rejection from peers	273-278		
Trusting friends to keep toilet use a secret – as could lead to teasing	313-319		
Wanting information given to friends to remain a secret and not common knowledge-control of stigma	325-329		
Fearful of embarrassing info being spread	450-454		
Embarrassing to talk about things that aren't regular (i.e. normal)	618-619		

Fear of being teased about IBD in secondary school prior to transition	904-909		
Fear that people might use what he has told them against him	1054-1058; 1067-1069; 1072-1075		
Fear of peers (he doesn't know well) not understanding increased toilet use [Fear of potential stigmatisation]	1092-1095		
Contemplated preparing for move to secondary by telling peers in primary about his IBD	1174-1178		
Telling teachers protects him from potential teasing	998-1002		
Fear that people might use what he has told them against him	1054-1058; 1067-1069; 1072-1075		
Relief that teachers all know/have been told	750-755	Telling teachers to protect from stigma/ having accidents	If I didn't tell them [teachers], if I just said, like I need to go to the toilet and they said no, because they don't really know, I would have a problem, because they wouldn't let me go. But, if they know about it and I said I need to go to the toilet, then they would let me go straightaway. (975-980)
Telling teachers collaboratively with mum	146-147		
Telling teachers protects from potential embarrassment (i.e. potential accidents)	149-151		
Forced to tell teachers to prevent embarrassing situation (i.e. potential accidents)	155-160		
Having toilet pass initiates/ facilitates conversations with staff who don't already know	774-777		

Telling teachers out of necessity – to avoid accidents	780-784		
Easier talking to teachers as they have duty to understand	786-788		
Safer talking to teachers rather than peers as they will not joke about it	794-796		
IBD related conversations with teachers are taken seriously	985-990		
Telling teachers prevents accidents and embarrassment at school	975-980; 1027-1032		
Mum talking to teachers on his behalf and their knowing was helpful	757-761	Mum's support in telling teachers protects against having accidents at school	If I was on my own, it would be a bit more harder for me to talk about it, [...] because I wouldn't really quite know what to say. But [...], if mum's with me, she can explain it a bit more detailed for them. (816-820)
Support from mum to talk to teachers is helpful	768-771		
Sharing responsibility to talk to teachers with mum is helpful	799-807		
Talking is made easier by mum 'lending him the words' [scaffolding]	818-820		
Mum sensitive to his desire to protect information [parents as protectors]	830-833		
Mum talking to teachers bridges gaps in his knowledge of IBD	822-825; 833-838		
Supported by mum to help teachers understand	1251-1253		

Relationship between Identity, disclosure and IBD			
Emerging Themes	Line Number		Quotes
Knowing more makes it easier to talk about IBD in secondary school	1258-1259; 1262-1263	Increased knowledge of IBD leads to increased disclosure	Because I've grown up a bit more I can explain things a bit more easier. [...] Because I know more about it. In primary school. I didn't know how it started and stuff. (1258-1259; 1262-1263)
Feeling more comfortable with illness leads to wanting to increase understanding of IBD amongst others	1239-1243	Increased acceptance of IBD leads to increased disclosure	But now that I've got to know a few more people and I've had it for a while, I've started telling a few more people, so that more people will know more and more people will understand why I go to the toilet and hospital. (1239-1243)
True identity begins to be revealed through talking with peers	1375-1378		
Feeling more knowledgeable and accepting of diagnosis following transition to secondary school	845-847		

Psychological benefits/ aids to disclosure			
Emerging Themes	Line Number	Sub theme	Quotes
Feeling genuinely cared for by friends who knew (physically)	374-377 & 380-381	Feeling cared for supported and less isolated by friends who he had told	[When] I came back from being sick, everyone else was like normal, saying, 'Tyler why were you in hospital?', But the three that I told were [...] making sure I was actually okay, okay. [...] Everyone else went straight out to break and played [...]. But they all bought me drinks and stuff, [...] to make sure I'm [...] all right, so I'm not flared-up as much. (368-381)
Genuine concern from peers is only attainable through telling	421-427		
Feeling understood/ less isolated	503-507; 528-529; 541-538		
Talking to reduce isolation of self & others	534-538		
Feeling comforted and supported after telling	1346-1348		
Freedom from worry of forced disclosure	1272-1275; 1279-1281	Liberation from suppression	We walked up and said, "Do you want to know why we go to hospital and have medicines a lot?", [...] and we told them all of our problems and what it does. [...] I told them that I have to keep going to the toilet and that I have an ulcer inside of me [...] and I have to have medicines in hospital. [...] It made me feel happy, a bit more happier, because a few more people knew about it. (1327-1330; 1333-1336; 1339-1340)
Telling people is liberating	1327-1330; 1333-1336; 1339-1340; 1355-1357		
Helpful talking to peers who have IBD too	474-477; 480-487	Talking to peers with shared experiences increases belonging and reduces isolation	I thought I was going to be the only one in the entire school, it turns out that I weren't. So, if loads of people know about one person has it, it will be okay if lots of people know that two people have it, so it will be quite a regular thing that a few people have. (597-602)
Talking to reduce isolation of self &	534-538		

others			
Talking to peers who have IBD = sense of belonging	557-564; 597-602; 625-628		
Feeling less alone/understood by peers who had similar procedures	676-678; 682-687		
Easier to talk to peers who understand him and his illness	1117-1119		
Easier telling people in secondary school than he had thought prior to transition – because there are others with IBD in his school	1229-1234		

Transition and disclosure			
Emerging Themes	Line Number	Sub theme	Quotes
Feeling like he restarted school when he started secondary school	23-27	Feeling like he restarted school when he started secondary school	Erm, like, because, there was loads of bigger kids and I was used to being the big kid in year six, it feels like I've restarted school again so I didn't know where to go, I didn't know where the lessons where, I was lost. (23-27)
Logistics of secondary school (i.e. more teachers) makes prospect of talking to teachers harder	1008-1011; 1013-1016	Logistics of secondary school (i.e. more teachers) makes prospect of talking to teachers harder	I thought, like, how am I going to speak to every single one who is in each class because sometimes they might not be in and I might not get the chance to speak to them. (1013-1016)

Psychological consequences/ inhibitors of disclosure			
Emerging Themes	Line Number	Sub theme	Quotes
Wanting to maintain a sense of privacy but this = difficult	608-610	Surrendering privacy	I usually talk to some of them a lot about it now, because I used to have to go up to hospital to have my medicine done and injections once every two weeks. Sometimes I have to have a camera inside me to [...] have a look around. I told them about that as well. (655-660)
Forced to tell because of repeated hospital appointments (talking out of sense of necessity)	655-660		
Trust is the foundation for telling peers	170-171	Fear of being out of control of information (after having told other about IBD)	[...] I thought them three [close friends he had disclosed to] had told everyone. [...] I thought I was going to be taken the Mickey out of in front of everyone but I wasn't. When we went to break I asked them, 'Why was everyone happy?' and, they just said, 'Because you were in hospital and you came out'. (411-416; 434-438)
Fear of being out of control of information	1237-1239		
Living in fear of being exposed by peers who know	411-416; 434-438		

IBD Diagnosis and School			
Emerging Themes	Line Number	Sub theme	Quotes
Scary being at school and not knowing what's wrong	113-114	Scary not knowing what was wrong with him in primary	I kept going to hospital and I didn't know what was going to happen, like they kept taking me is into rooms and giving me medicines and I do know what was happening really. (57-61)
Scary not knowing what was going on when initially diagnosed	57-61		

Appendix 12 - Audit Trail: (a) Super-ordinate themes clustered and master themes for all interviews

Stigma Management		
Sub-Theme	Participant	Emerging themes
Fear of negative peer behaviour 7: Holly, Will, Danny, Sunaya, Ella, and Dean	Tyler	a. Fear of teasing and peer rejection
	Holly	<ul style="list-style-type: none"> Defending against teasing by not talking Not being able to deal with diarrhoea related comments/ teasing Fear of diarrhoea-related teasing
	Will	<ul style="list-style-type: none"> Fear of vulnerability (e.g. bullying) through loss of control of information Telling people who will not affect social identity Not talking as a strategy for coping with school life rather than not being capable to. Leakage of information could lead to bullying Talking risks rejection Living in fear of potential stigmatisation/ bullying (e.g. bullied because of diagnosis)
	Dean	<ul style="list-style-type: none"> Fear of accidental disclosure leading to teasing Talking about something that isn't widely understood is stigmatising (Singles him out as different) -> risks rejection
	Ella	<ul style="list-style-type: none"> Fear of IBD talk disgusting people Relived – secret was kept safe

	Danny	<ul style="list-style-type: none"> ◦ Telling invites embarrassment ◦ Fear of teasing/ stigma
	Sunaya	<ul style="list-style-type: none"> ◦ Toilet talk is Taboo – so says mum
Fear of disease burden 3: Holly, Ella, Will	Holly	<ul style="list-style-type: none"> ◦ Covering information to make teachers feel more comfortable – ‘not getting more information than they bargained for’ ◦ Afraid that talking will consume fun
	Ella	<ul style="list-style-type: none"> ◦ Afraid that talking will consume fun
	Will	<ul style="list-style-type: none"> ◦ Not wanting to burden people with diagnosis.
c. The safety net of teacher and parental support 7: Ella, Will, Tyler, Holly, Sunaya, Dean, Danny	Will	<ul style="list-style-type: none"> ◦ Talking to teachers to protect from having an accident ◦ Shielded from embarrassment of repeated self-disclosure by others (teachers)
	Ella	<ul style="list-style-type: none"> ◦ Disclosure mediated through parents protects from having an accident/ further embarrassment ◦ Toilet card given by teachers prevent accidents
	Tyler	<ul style="list-style-type: none"> ◦ Telling teachers to protect from stigma/ having accidents ◦ Mum’s support in telling teachers protects against having accidents at school

	Holly	<ul style="list-style-type: none"> ◦ Mum as supporter and protector ◦ Mum could have bridged the gap - saying the things that she couldn't bring herself to say
	Dean	<ul style="list-style-type: none"> ◦ Mum talking protects privacy ◦ Mum talking protects from accidents/ further embarrassment
	Sunaya	<ul style="list-style-type: none"> ◦ Mum talking protects from accidents/ further embarrassment ◦ Mum talking protects from repeated disclosure ◦ Putting trust in parent to make decision to talk -> Mum keeps her safe from appearing different
	Danny	<ul style="list-style-type: none"> ◦ Mum talking protects from accidents/ further embarrassment
d. Balancing peer curiosity with stigma limitation 6: Sunaya, Ella, Holly, Tyler, Danny, Will	Holly	<ul style="list-style-type: none"> ◦ 'Telling the bare minimum' – protecting from embarrassment/ Relief from awkwardness of having to explain illness ◦ 'Saying enough to satisfy' peers curiosity and need to protect self.
	Tyler	<ul style="list-style-type: none"> ◦ Full disclosure to prevent more stigmatising assumptions – linking symptoms to medical condition
	Will	<ul style="list-style-type: none"> ◦ 'Getting tired of saying it' - Limiting information given to protect from emotional strain of being judged (social judgements) ◦ Don't ask, don't tell- Giving more information only if asked
	Ella	<ul style="list-style-type: none"> ◦ Don't ask, don't tell- Not revealing 'secret' identity unless asked ◦ Safer talking about appointments, procedures -> doesn't identify her as abnormal ◦ Torn between need to protect (from stigmatisation) and need to tell
	Danny	<ul style="list-style-type: none"> ◦ Protecting self from teasing by giving limited and/or vague information

	Sunaya	◦ Limiting talk to avoid stigmatisation/ embarrassment
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Relationship to identity and IBD		
Sub-Theme	Participant	Emerging themes
Dissociation 4: Dean, Ella, Sunaya, Will	Ella	◦ Not telling others – hoping that condition is a temporary state not permanent part of identity ◦ Not talking = way of dissociating/ not re-living the trauma of diagnosis- Not talking about the 'long story'
	Sunaya	◦ Not talking (at school) helps dissociate from the illness -> Creates distance between illness and school
	Dean	◦ Not talking to prevent 'Loss of normal self' - Denying the reality of IBD diagnosis by not talking about it ◦ 'Normal Self' is lost through talking - Forced to acknowledge the reality of the illness through talking with others
	Will	◦ 'Not going right in depth' - Desire to suppress past (and future) experiences of embarrassment
Tension between IBD and 'normality'	Will	◦ Not talking to maintain sense of 'Normality' - 'I want to be the same' (Desire to be socially accepted and not viewed as different). ◦ Relief at not being treated normally

6: Holly, Dean, Sunaya, Danny, Ella and Will	Dean	<ul style="list-style-type: none"> ◦ Limiting talking to maintain a sense of normality ◦ Let's not talk about it – Wanting friends not to know/ care to remain normal ◦ Talking repeatedly is exposing– incapable of passing as normal
	Danny	<ul style="list-style-type: none"> ◦ Limiting talking to maintain a sense of normality
	Holly	<ul style="list-style-type: none"> ◦ Desperately clutching on to sense of control over her identity - Last remaining element of control over identity ◦ Talking risks consuming old identity – attract undesired identity- ‘sick girl’ ◦ Talking invites overprotection – ‘treating me like a child’ ◦ Talking invites pity
	Ella	<ul style="list-style-type: none"> ◦ Fear of being Overprotected - people ‘being too nice’- (overprotected, babying)
	Sunaya	<ul style="list-style-type: none"> ◦ Not talking to retain sense of normality - Wanting to ‘get on’ with school ◦ Secret is safe – Normality may continue
Beginning to come to terms with IBD 5: Will, Tyler, Holly, Ella, Danny	Danny	<ul style="list-style-type: none"> ◦ Biopsychosocial immaturity hinders talking - in primary
	Holly	<ul style="list-style-type: none"> ◦ Biopsychosocial immaturity hinders talking - in primary
	Ella	<ul style="list-style-type: none"> ◦ Time to recover from trauma of diagnosis helps to talk
	Will	<ul style="list-style-type: none"> ◦ Increased knowledge in secondary means having increased control and power to talk about IBD
	Tyler	<ul style="list-style-type: none"> ◦ Increased knowledge of IBD leads to increased disclosure ◦ Increased acceptance of IBD leads to increased disclosure

Acceptance 3: Holly, Will, Ella	Holly	◦ Talking as revelation of true identity – talking to create acceptance
	Ella	◦ Laying bare true identity/ truth about diagnosis- Nothing else to tell
	Will	◦ Need to reveal authentic self

Disclosure as a double edged sword		
Sub-Theme	Participant	Emerging themes
Emotional support 5: Will, Holly, Danny, Tyler & Ella	Will	<ul style="list-style-type: none"> ◦ Talking to peers with shared experiences reduces isolation/ feel understood ◦ Talking to reduce isolation/ feel understood
	Dean	◦ Balancing need to maintain privacy and not ostracise friends
	Holly	<ul style="list-style-type: none"> ◦ Not talking means you might end up alone ◦ Honesty (detailed talking) increases support, validation and understanding
	Tyler	<ul style="list-style-type: none"> ◦ Feeling cared for supported and less isolated by friends who he had told ◦ Talking to peers with shared experiences increases belonging and reduces isolation
	Ella	<ul style="list-style-type: none"> ◦ Feeling 'looked after' - after telling ◦ Talking to teacher with shared experiences - reduces isolation/ feel understood
	Danny	<ul style="list-style-type: none"> ◦ Feeling understood by staff who has IBD (dinner lady) ◦ Feeling "looked out for and supported" through talking

'Coming out of the closet' of invisible illness 5: Holly, Ella, Danny, Tyler, Will	Ella	<ul style="list-style-type: none"> ◦ Liberation: 'Getting it out of her system' – feeling free from psychological stress of suppressing secret
	Danny	<ul style="list-style-type: none"> ◦ Talking as liberation ◦ "Bottling things up" - Not talking as suppression/ Holding back ◦ feeling contained after telling peers
	Tyler	<ul style="list-style-type: none"> ◦ Liberation from suppression
	Will	<ul style="list-style-type: none"> ◦ Talking to friends is liberating ◦ Talking to prevent feeling like a liar -> relief from guilt of feelings of deceit ◦ Feeling contained after telling peers
	Holly	<ul style="list-style-type: none"> ◦ Guilt at not telling complete truth (morals and values)
Losing tight hold on information 5: Danny, Ella, Sunaya, Tyler, Will	Tyler	<ul style="list-style-type: none"> ◦ Fear of being out of control of information (after having told other about IBD)
	Will	<ul style="list-style-type: none"> ◦ Losing grip on control of information ◦ Not knowing who knows
	Sunaya	<ul style="list-style-type: none"> ◦ Fear of information being haphazardly spread to others
	Ella	<ul style="list-style-type: none"> ◦ Relieved that news wasn't spread to others
	Danny	<ul style="list-style-type: none"> ◦ Fear of information shared haphazardly ◦ Torn between need to protect (from stigmatisation) and need to tell ◦ Mixed feelings: Feeling regretful vs. feeling satisfied AFTER talking ◦ Living with regret -> regretted telling

Disabling attitudes and reactions 2: Holly and Will	Holly	<ul style="list-style-type: none"> ◦ Feeling betrayed by other's ignorance/ lack of understanding ◦ Battling to 'put people straight' - battling against people's ignorance ◦ Fighting a losing battle against people's ignorance ◦ Not taken in' - Not feeling fully understood
	Will	<ul style="list-style-type: none"> ◦ Lack of talking is projected on to others as Anger for lack of support ◦ Misunderstood and unsupported by friends who knew about his IBD.
Surrendering privacy 4: Dean, Holly, Tyler, Will	Dean	<ul style="list-style-type: none"> ◦ Protecting privacy by not talking/ swearing at people who ask questions
	Holly	<ul style="list-style-type: none"> ◦ Forced to surrender privacy- Talking is a violation of privacy ◦ Forced to tell (as it became harder to hide) – 'no way around it' ◦ Not knowing how much to tell
	Will	<ul style="list-style-type: none"> ◦ Maintaining Privacy - not talking about it to prevent feeling mortified ◦ Invisibility (of illness) grants freedom to choose to talk or not talk ◦ Visibility of illness forces to tell/ talk (i.e. symptoms, appointments, treatment, necessary apartments at school)
	Tyler	<ul style="list-style-type: none"> ◦ Surrendering privacy

Appendix 12 (b)- Audit trail: Themes from all interviews

Will – interview 1

1. Self-Protection

- a. Telling people who will not affect social identity
- b. Not talking as a strategy for coping with school life rather than not being capable to.
- c. 'Getting tired of saying it' - Limiting information given to protect from emotional strain of being judged (social judgements)
- d. Maintaining Privacy - not talking about it to prevent feeling mortified

2. Control of information

- a. Leakage of information could lead to bullying
- b. Visibility of illness forces to talk (i.e. symptoms, appointments, treatment, necessary
- c. Talking to teachers to protect from having an accident
- d. Don't ask, don't tell- Giving more information only if asked
- e. Invisibility (of illness) grants freedom to choose to talk or not talk
- f. Losing grip on control of information

3. Protected by others

- a. Shielded from embarrassment of repeated self-disclosure by others (teachers)

4. Personal reasons for talking

- a. Not talking to maintain sense of 'Normality' - 'I want to be the same' (Desire to be socially accepted and not viewed as different).
- b. 'Not going right in depth' - Desire to suppress past (and future) experiences of embarrassment

5. Positive/ personal gains of talking

- a. Talking to reduce isolation/ feel understood
- b. Need to reveal authentic self
- c. Talking to friends is liberating (from fear of rejection?)
- d. Talking to prevent feeling like a liar -> relieve from guilt of feelings of deceit
- e. Talking to peers with shared experiences reduces isolation/ feel understood
- f. Feeling contained after telling peers

6. Protecting others

- a. Not wanting to burden people with diagnosis.

7 Acceptance vs. rejection – social judgements

- a. Anticipatorily awaiting news to be digested/ for social judgement to be passed
- b. Relief at not being treated normally
- c. Talking risks rejection

8. Transition to secondary school

- a. Increased knowledge means having increased control and power to talk about IBD

9. Living with uncertainty

- a. Lack of talking is projected on to others as Anger for lack of support
- b. Living in fear of potential stigmatisation/ bullying (e.g. bullied because of diagnosis)

- c. Not knowing who knows

10. Misunderstood/unsupported

- a. Misunderstood and unsupported by friends who knew about his IBD

Tyler – interview 2

1. Stigma management

- b. Fear of teasing and peer rejection
- c. Giving limited information to peers to protect from stigmatisation and satisfy peer curiosity
- d. Full disclosure to prevent more stigmatising assumptions – linking symptoms to medical condition
- e. Telling teachers to protect from stigma/ having accidents
- f. Mum's support in telling teachers protects against having accidents at school
- g. Less stigmatising to talk about Easier procedures/ treatment rather than symptoms (more normal)

2. Relationship between Identity, disclosure and IBD

- a. Increased knowledge of IBD leads to increased disclosure
- a. Increased acceptance of IBD leads to increased disclosure

3. Psychological benefits/ aids to disclosure

- a. Feeling cared for supported and less isolated by friends who he had told
- b. Liberation from suppression
- c. Talking to peers with shared experiences increases belonging and reduces isolation

4. Psychological consequences/ inhibitors of disclosure

- a. Surrendering privacy
- b. Fear of being out of control of information (after having told other about IBD)

5. IBD Diagnosis and School

- a. Scary not knowing what was wrong with him in primary

6. Transition and disclosure

- a. Feeling like he restarted school when he started secondary school
- b. Logistics of secondary school (i.e. more teachers) makes prospect of talking to teachers harder

Sunaya – interview 3

1. IBD talk mediated by Mum

- a. Not my duty to tell- Mum should tell for me
- b. Mum talking protects from repeated disclosure
- c. Mum talking protects from accidents/ further embarrassment
- d. Putting trust in parent to make decision to talk -> Mum keeps her safe from appearing different

2. STIGMA LIMITATION

- a. Limiting talk to avoid stigmatisation/ embarrassment
- b. Toilet talk is Taboo – so says mum

3. NOT TALKING TO MAINTAIN SENSE OF NORMALITY

- a. Not talking to retain sense of normality - Wanting to 'get on' with school
- b. Not talking (at school) helps dissociate from the illness -> Creates distance between illness and school
- c. Secret is safe – Normality may continue

4. FEAR OF STIGMATIZATION

- a. Fear of information being haphazardly spread to others

Dean – interview 4

1. Privacy

- a. Balancing need to maintain privacy and not ostracise friends
- b. Protecting privacy by not talking/ swearing at people who ask questions
- c. Mum talking protects privacy

2. Maintaining a sense of normality

- a. Limiting talking to maintain a sense of normality
- b. Let's not talk about it – Wanting friends not to know/ care to remain normal
- c. Talking repeatedly is exposing– incapable of passing as normal

3. Fear of stigmatisation/ teasing

- a. Fear of accidental disclosure leading to teasing
- b. Talking about something that isn't widely understood is stigmatising (Singles him out as different) -> risks rejection
- c. Mum talking protects from accidents/ further embarrassment

4. Talking leads to 'death of self'

- a. Not talking to prevent 'Loss of normal self' - Denying the reality of IBD diagnosis by not talking about it
- b. Normal Self' is lost through talking - Forced to acknowledge the reality of the illness through talking with others

Danny – Interview 5

1. Psychological consequences of disclosure and suppression

- a. Talking as liberation
- b. “Bottling things up” - Not talking as suppression/ Holding back
- c. Feeling contained after telling peers

2. Psychological benefits of Disclosure

- a. Feeling ‘looked out for and supported’ through talking
- b. Feeling understood by staff who has IBD (dinner lady)

3. Living with mixed feelings

- a. Torn between need to protect (from stigmatisation) and need to tell
- b. Mixed feelings: Feeling regretful vs. feeling satisfied AFTER talking
- c. Wanting to tell but not knowing trust/ “who to turn to”

4. Psychological consequences of disclosure

- a. Fear of information shared haphazardly leading to bullying/ stigmatisation
- b. Living with regret -> regretted telling
- c. Waiting for social adjudication - accepted or rejected?
- d. Limiting talking to maintain a sense of normality

5. Psychological Inhibitors to disclosure

- a. Telling invites embarrassment
- b. Fear of teasing/ stigma

6. Stigma Limitation

- a. Protecting self from teasing by giving limited and/or vague information

7. Psychological aids to disclosure

- a. Mum talking protects from accidents/ further embarrassment

8. Transition to Secondary School

- a. Biopsychosocial immaturity hinders talking - in primary

Holly- Analysis – interview 6

1. Disabling attitudes/ reactions

- a. Battling to 'put people straight' - battling against people's ignorance – (seen as Hypochondriac)
- b. Fighting a losing battle against people's ignorance – (seen as drama queen)
- c. Feeling betrayed by other's ignorance/ lack of understanding
- d. 'Not taken in'- Not feeling fully understood

2. Enabling/ supportive attitudes/ reactions

- a. Talking increases access to practical support
- b. Honesty (detailed talking) increases support, validation and understanding
- c. Not talking means you might end up alone

3. Privacy

- a. Not knowing how much to tell
- b. Forced to surrender privacy- 'Privacy invaded' – Talking is a violation of privacy
- c. Forced to tell (as it became harder to hide) – 'no way around it'

4. 'Keeping it short'

- a. Talking invites pity
- b. Talking invites overprotection – 'treating me like a child'
- c. Covering information to make teachers feel more comfortable – 'not getting more information than they bargained for'
- d. Afraid that talking will consume fun
- e. 'Saying enough to satisfy' peers curiosity and need to protect self.

5. Stigma – Teasing and embarrassment

- a. 'Telling the bare minimum' – protecting from embarrassment
- b. Not being able to deal with diarrhoea related comments/ teasing
- c. Fear of diarrhoea-related teasing
- d. Defending against teasing by not talking

6. Identity

- a. Talking as revelation of true identity – talking to create acceptance
- b. Talking risks consuming old identity – attract undesired identity- 'sick girl'
- c. Desperately clutching on to sense of control over her identity - Last remaining element of control over identity
- d. Biopsychosocial immaturity hinders talking in primary

7. Internal/ Psychological states

- a. Guilt at not telling complete truth (morals and values)

8. Support from mum

- a. Mum as supporter and protector
- b. Mum could have bridged the gap - saying the things that she couldn't bring herself to say

Ella- interview 7

1. Psychological benefits of Disclosure

- a. Feeling 'looked after' - after telling
- b. Liberation: 'Getting it out of her system' – feeling free from psychological stress of suppressing secret

2. Psychological aids to disclosure

- a. Talking to teacher with shared experiences - reduces isolation/ feel understood
- b. Toilet card given by teachers prevent accidents
- c. Disclosure mediated through parents protects from having an accident/ further embarrassment

3. Fearing things/ Normality will change after telling

- a. Feeling contained by reactions show by friends after telling them
- b. Not telling others – hoping that condition is a temporary state not permanent part of identity
- c. Not talking = way of dissociating/ not re-living the trauma of diagnosis- Not talking about the 'long story'
- d. Fear of being Overprotected - people 'being too nice'- (overprotected, babying)
- e. Time to recover from trauma of diagnosis helps to talk
- f. Safer talking about appointments, procedures -> doesn't identify her as abnormal
- g. Laying bare true identity/ truth about diagnosis- Nothing else to tell

4. Psychological Inhibitors to disclosure

- a. Fear of IBD talk disgusting people
- b. Afraid that talking will consume fun

5. Living with mixed feelings

- d. Torn between need to protect (from stigmatisation) and need to tell

6. Stigma limitation

- a. Don't ask, don't tell- Not revealing 'secret' identity unless asked
- b. Relieved – secret was kept safe

Appendix 13 - Extract from reflective diary

Below is an extract taken from my reflective research diary. It captures my reflections following a monthly peer supervision session, attended by colleagues also using IPA (roughly about 5-6 people). Within this session I discussed my experience of the final stages of analysis prior to my beginning cross-analysis:

During the meeting I spoke of my feelings of annoyance when analysing transcripts where participants talked superficially about IBD, or very little about experiences of actually disclosing IBD to others. My peers made me reflect on this annoyance and wondered if this annoyance related to my having to engage with the data on a more interpretative level, which may have felt more labourious. My colleagues helped remind me about the importance of the hermeneutic circle and the dynamic relationship in IPA between the part (in this case particular extracts of text) and the whole (in this case the transcript itself). This made me wonder if perhaps I should reframe this frustration as an invitation to engage with the data on a more interpretive amount. Given the iterative nature of an IPA analysis, I believe it might be sensible to go back and review my analysis of the transcripts where I note myself feeling in this way to ensure that I have captured participants' understandings to the best of my abilities as a researcher who is engaged in a double hermeneutic.

I also discussed my noticing, compared to the analysis of other transcripts, not dropping as many emergent themes from the analysis of certain transcripts (namely the transcripts of Ella, Holly, Will and Tyler). I shared my concerns that this might reflect an inability to 'bracket' my previous knowledge and assumptions. The group helped me to ponder a number of reasons for this. One hypothesis was that this might relate to the 'richer' nature of the data collected from these interviews (i.e. talked in greater depth about all topics). Another thought was that this might be because I might have been more acclimatised to analysing transcripts in an IPA fashion when the time came to explore the transcripts of certain participants. The group also asked if this might have to do with these participants' experiences resonating more closely with my own. Given that I have IBD myself, this has been my greatest fear throughout the

study; that I might influence the interpretation in such a manner and I feel I have worked hard to adopt a 'phenomenological attitude' from the beginning (e.g. keeping a reflective diary and regularly attending these groups early on in the research process). Whilst I understand that bracketing can only ever be partially achieved (Smith et al., 2009) I wonder if, again, it might be worth my going back to the data to ensure that my analysis and the interpretations made are grounded in the data.

Whilst I have not begun my cross analysis as yet, my peers also asked me if I had a sense of what participants felt was important in terms of understanding their experiences of disclosing IBD at school. I shared that many, if not all, of the participants spoke of disclosure or non-disclosure within the context of experienced or feared IBD related bullying and teasing. The group helped me to reflect on the participants' contexts, as well as my own contexts, that might inform my assumptions when I come to cross-analyse narratives detailing such experiences. My peers helped bring to my attention that, whilst I had experience of a similar system, that I did not attend a primary or secondary school in the UK. This made me wonder if perhaps schools in Malta might be smaller to the one's attended by my participants and consequently might have been less of a scary place. They also reminded me that how real the threat of bullying and teasing is, irrelevant of whether you have a chronic illness or not. Given my age, perhaps I have underestimated how scary the threat of bullying may be to these young people and how strong the desire not to give potential bullies any 'ammunition' by making differences known and visible. I will try to keep these thoughts in mind when I do carryout my cross analysis.

Appendix 14- Synopsis of participants experiences of disclosure and illness

Participants	Course of illness in secondary school	Course of illness in primary school	Synopsis of experiences of disclosure of IBD to date	Current treatments/ procedures (Only listed if mentioned in the interview)
Will	<ul style="list-style-type: none"> No significant flare-ups. No hospitalisation. 	<ul style="list-style-type: none"> flare-ups and periods of remission 	disclosed to friends himself in secondary and primary (up to three) Mum disclosed to teachers in primary and secondary	<ul style="list-style-type: none"> Once fortnightly Adalimumab²¹ injections Had previously been on a medical liquid-only diet (in secondary)
Tyler	<ul style="list-style-type: none"> experienced moderate flare-ups required hospitalisation 	<ul style="list-style-type: none"> flare-ups and periods of remission 	disclosed to friends himself in secondary and primary (over 5) He and his mother disclosed to teachers in secondary together His mother disclosed to teachers in primary	<ul style="list-style-type: none"> Not mentioned
Holly	<ul style="list-style-type: none"> Experienced moderate flare-ups Required hospitalisation 	<ul style="list-style-type: none"> flare-ups and periods of remission 	<ul style="list-style-type: none"> disclosed to her friends herself (over 5) disclosed to teachers in secondary by herself 	<ul style="list-style-type: none"> Not mentioned
Sunaya	<ul style="list-style-type: none"> No significant flare-ups. No hospitalisation. 	<ul style="list-style-type: none"> flare-ups and periods of remission 	<ul style="list-style-type: none"> no self-disclosure: only by her mum and only to teachers 	<ul style="list-style-type: none"> Not mentioned
Danny	<ul style="list-style-type: none"> No significant flare-ups. No hospitalisation. 	<ul style="list-style-type: none"> flare-ups and periods of remission 	<ul style="list-style-type: none"> disclosed to his friends himself (up to three friends) Mum disclosed to teachers in primary and secondary 	<ul style="list-style-type: none"> Not mentioned
Dean	<ul style="list-style-type: none"> No significant flare-ups. No hospitalisation. 	<ul style="list-style-type: none"> flare-ups and periods of remission 	<ul style="list-style-type: none"> no self-disclosure: only by her mum and only to teachers 	<ul style="list-style-type: none"> Not mentioned
Ella	<ul style="list-style-type: none"> Experienced moderate flare-ups No hospitalisation 	<ul style="list-style-type: none"> flare-ups and periods of remission 	<ul style="list-style-type: none"> disclosed to her friends herself (up to two friends) Mum disclosed to teachers in primary and secondary 	<ul style="list-style-type: none"> Iron infusions (once weekly) as an outpatient

²¹ Used to treat Ulcerative Colitis when other drugs have not worked or have caused major side effects

Appendix 15 - Modifications to text

This appendix gives an example of three extracts that were reduced for the purpose of this thesis.

Example 1

Extract in thesis:

"[...] Everyone can have an injection and stuff like that, but because the colitis is a part of me, erm, because it's just telling someone about [...] a part of you [...], it's easier telling people like what I have to have done." (Tyler 709-718)

Full Text:

"I don't really know. It's just that the injections and medicines in ain't really, like, what I have to, like, like because the colitis is part of me, but the injections ain't, and like, everyone can have an injection and stuff like that, but because the colitis is a part of me, erm, because it's just telling someone about, like what a part of you and not erm, it's easier telling people like what I have to have done." (Tyler 709-718)

Example 2

Extract in thesis:

"[...] There is a group of girls [...] I talk to them, but I don't talk to them about my personal problems. So, I can't really trust that what I told them would stay between me and them, that they wouldn't take [what I say] and use it against me. So I tell them just enough to satisfy them really. Like, I say it has something to do with my stomach, it causes pain and that it makes me feel sick and that's it. I then say, "If there's anything else you want to ask me, you can do", then I change the subject." (Holly 854-861)

Full text:

"Like, now at school, there is me and my group of friends and then there is a group of girls that at lunchtime or break we sit down and eat together. I talk to them, but I don't talk to them about my personal problems. So, I can't really trust that what I told them would stay between me and them. That they wouldn't take and use it against me. So I tell them just enough to satisfy them really. Like I say something to do with my stomach, it causes pain and this makes me feel sick and that's it. I then say, "If there's anything else you want to ask me, you can do", then I change the subject." (Holly 854-861)

Example 3

Extract in thesis:

"I didn't tell her [best friend] anything else after that, because that was it, what I'd told her. There was nothing else to tell. [...] I told her about my illness and what happened and everything, so I told her the whole story really and, [...] so, there was nothing left to tell. I told her the story from the beginning, so she knew everything about me and it felt good." (Ella 403-413)

Full text:

Ella: I was [pause] happy because, like, erm I thought she would panic but she didn't. So I was okay. And I didn't tell her anything else after that because that was it, what I'd told her. There was nothing else to tell.

Researcher: can I just check with you what you mean when you say there's nothing else to tell?

Ella: Because I told her about my illness and what happened and everything, so I told her the whole story really and, erm, so there was nothing left to tell. I had told her the story from the beginning so she knew everything about me and it felt good. (Ella 403-413)

Appendix 16- Additional information sheet given to participants after interviews



Additional information

Thank you for taking part! After the interview the recordings I listen to, will be typed up and analysed. The results will be written up as a thesis and could also be written up in other forms such as a journal article. If you have told me that you would like this, a summary of the results will be sent to you once the project is finished.

Further support

Your IBD nurses at _____ Hospital: _____ and _____ should be able to provide help or support if you need it. They can be reached on the following number:

_____ Ext _____.

If feel that you need extra support or advice then the following organisation may be helpful:

NACC Contacts

Call: 0845 130 3344

Who are the Contacts?

- ⤴ Contacts are usually people with Crohn's or Colitis or their relatives
- ⤴ They are volunteers, and all have been chosen and trained for their listening skills.

What do they Offer?

- ⤴ emotional help and support at the end of the telephone to people with IBD and their families and friends
- ⤴ Contacts can offer support at times when you may feel that you wish to talk through problems, situations or feelings with someone outside your immediate circle of family, friends or health care professionals.



When can I call them?

- ⤴ Every Monday, Tuesday, Wednesday, Thursday or Friday (excluding Bank Holidays) from 1 - 3.30 pm and 6.30 – 9 pm .

Some Helpful Websites:

Websites for Young People with IBD

- UC and Crohn's site for teens – site offering teens practical advice on handling their illness, facts on nutrition, school survival tips and more: www.ucandcrohns.org



- Children with Crohn's and Colitis website: www.cicra.org



- Growing Up IBD website - Dedicated to raising awareness about Inflammatory Bowel Disease : www.growingupibd.org

Other IBD related Websites (containing information for people of all ages):

- Website for The National Association for Colitis and Crohn's Disease (NACC)- IBD charity that brings together people of all ages who have been diagnosed with IBD, their families and the health professionals involved in their care: www.crohnsandcolitis.org.uk



- Website for Crohn's Zone- Crohn's Zone is a friendly interactive forum based community for people all over the world with Crohn's disease and ulcerative colitis: www.crohnszone.org

